

A CANCER JOURNEY

A PERSONAL ODYSSEY OF FAITH



JENNY COCKSEY

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Biography of Author



Jenny Cocksey was born in Whangarei, New Zealand in February 1947. After completing her education she left New Zealand to travel, firstly hitchhiking around the Mediterranean Sea, across North Africa and back up to Syria, Turkey and Greece.

She and her first husband settled in Britain but spent much of their time on expatriate engineering contracts in North and West Africa. They have two daughters, Nicki and Miranda.

In 1986 Jenny and her second husband, Brian, seemed to be led together through an interest in Ancient Egypt. Since then they worked on research into the nature and significance of coincidence as well as psychic communication.

Jenny returned to New Zealand in January 1995 with Brian but became very depressed at the way she now felt rejected by her country to which she had been faithful throughout her travels. She could see how the New Zealand "do as I say and don't stand out from the crowd" culture had formed her. She could also see the detrimental effect it was having on Brian in his professional capacity where he didn't suffer fools gladly. His tendency to be always honest and straight meant he was rejected and in time he became very frustrated and depressed. The stresses for both of them became almost unbearable.

Jenny was diagnosed with cervical cancer in August 2000

and started the long journey to what God intended. It certainly was a hard road.

Sadly Jenny passed on 14th April 2009 at 12.29am, her 19th wedding anniversary. She did it her way, God's way. God was always with her and now she is with God.

Dedication

To my husband, Brian
Without whose love
I would not have the strength of make this journey

*I kissed him gently on top of his bald head and
said "Have I told you how much I love you?"
Then, "You know - this cancer has brought us so
much closer together ..."*

"But for how long?" was his quiet reply.

Why this Book?



It is pretty tough being told you have cancer. There is the numbness, followed by all sorts of feelings and reactions. Then the thoughts come tumbling.

There are considerations about treatment and about practical matters. Over all, there is the fear. Life is going to change - or perhaps not exist for much longer. And there is the concern for those who would be left behind.

It is not just the cancer patient but the whole family. Friends, too, don't know how to react as often it feeds into their own fears about their health or mortality. Or, too often, it reminds them of losses of their own.

I have decided to set down this very personal story. When distressed, I would sit at my computer and write, setting down exactly how I was feeling. For this reason, it is very much in the style of a journal, recording thoughts and feelings. I felt so much hurt and anger and confusion and fear - all natural, I am sure. Originally, it was just letters to people and things I had written in the depths of my despair or indecision. I found it very therapeutic to write down my thoughts and I only wish I had been more regular about it. However, the very effort of trying to continue to exist takes up so much energy.

Personally, I have found it so helpful to read of the experiences of others. One of the things I find hardest is that there is little in the way of support groups. It would give me the utmost satisfaction to be able to get groups of people together

to gain strength from each other. I can't see that happening in the near future, so this is the next best thing.

Although I have decided to take the alternative route, that doesn't mean to say that it is the right choice for everybody. I would suggest seeking all the advice you can, making sure you do get the information you need. Weigh it all up, and do what feels right for you, deep down in your heart. Then put your very soul into making your chosen path work.

I hope others finding their way along this path will draw comfort from this book. I hope, too, that it can give an insight into the complex mental and emotional struggles that each person will inevitably have to go through. To know you are not alone, that you are not going crazy, that you can get through it is such a comfort, especially in those darker or more inward looking moments.

I don't know whether I will overcome this. The signs don't look especially good. But I will continue to do my best to keep my body and mind as strong as possible. And my spirit is willing. With my strong faith in God, my determination and my love of life, perhaps I will become fully well again. In the meantime, I have gained so much from having cancer. I see it almost as a gift.

Even should I succumb, then this stage of my life will have taught me so much and I am grateful for that. It has also brought my daughters closer to me and improved communication. I have learnt, too, how important a close marriage can be.

So take my personal feelings, treat them gently as you would treat yourself, and know that, through adversity, you can perhaps become a stronger and wiser person. The struggle has left me with an awareness of the value of life and perhaps even a renewed sense of purpose.

Jenny

Introduction



Here I am, four and a half years after diagnosis with cervical cancer. Five years is considered good survival with orthodox treatment. I have rejected that in favour of a way that seems right to me, a way which seems in tune with what nature intended - that I do everything I can to balance every system in my body so that it can function properly and overcome this disease. It goes against everything I have tried to do so far to now allow my body to be poisoned. This may not be the right option for some people, for the way I have been guided to take is both very difficult and very lonely.

But from the shock and the fear and the anger, I have now found a peace and a fulfilment. Maybe I will beat the odds - and by rights I should now be dead, according to the type of cancer I have and all the dire warnings of the doctors. Or perhaps I won't beat the odds. Only God knows the future. But I do know that I am giving it my best try.

For nigh on twenty years, my husband, Brian, and I have lived our lives guided by coincidence and intuition. Why should I change that approach now? *Coincidence is* [indeed] *God's way of remaining anonymous* as the sign outside Holy Trinity Church in Tauranga said. I saw that in 1997, three years before my diagnosis. Really it was just a confirmation of what we both knew already, but I do trust in that and seek God's guidance as

to what to do. It is often scary, but then I feel a sense of peace and a rightness coming upon me.

I know that if God intends me to survive this, then I will. If He does not, then I will die, whether or not I have orthodox treatment. That is not to say that I just sit back and wait for a miracle. No - every day I must struggle to do my best, to work with God.

So I have gathered around me a group of people, orthodox and alternative, whom I trust to help me. I have found most of these people through coincidence – been guided, if you like. They help give me strength when I falter, help guide me. But most of all I rely on my husband, Brian, for his love and support, even when he himself is not at all well. Together we seek to fulfil what God wants. I must stick around for a bit longer to finish our books and our work. That purpose helps to keep me going.

I have learnt so much from having cancer - and have actually come to see it as a blessing. I am grateful for the experience. For the first time in my life, I have been able to stand up and say “This is my body. This is my mind. And this is my spirit. I will take responsibility for myself. I will consider everything carefully and then I will make a guided choice.” So, whatever the outcome, I will have the peace which comes from being in control of my own destiny. And I trust in God to do as He sees fit with my life as I allow Him to guide me towards that destiny.

Perhaps this very personal story will help others faced with similar choices. Perhaps they will be able to see that cancer can help them to find out what is right for them, what is the best path for the remainder of their lives, whether the time left be long or short. I have been guided in my choices by my faith, my experience and my intuition - you could refer to these as my mind, my body and my spirit, I suppose.

Jenny Cocksey

The spirit can communicate with the mind and the body, and together they make the whole - and this is true healing. That comes from inside, rather than from without. But each should seek to find the best way for them and live life as fully as possible to their allotted span.

Easter Sunday, 2005

Preface



This is the story of the emotions and fears of trying to deal with cancer, but it is also the story of the gradual overcoming of deep emotional problems. In large part, this has been made possible because my struggle with cancer has made me stronger and more able to stand up for what I feel is right for me.

My return to New Zealand after almost 17 years living overseas has been a devastating experience for me. Coming here was even worse for my English husband. I had always looked on this as home and was quite excited to be coming back at last and felt we could make a valuable contribution. That was not to be. Tall poppies, anyone with ideas, anyone different, especially if they are the despised British, is cut down and destroyed. The only way to thrive in New Zealand is to just give in and become unthinking, unquestioning and compliant. We just cannot do that. They talk so much of the costs of compliance in business. Little do they realise the true costs of compliance for all.

Anyway, we came under tremendous stress on finding that this place would never be home for either of us. We just did not have a home anywhere any more. We were now effectively exiled from England because of the low standard of living and low wages here in New Zealand compared to England and the rocketing property prices there. This has led to a deep depression for both of us. To have nowhere you belong, and to

have no voice and to be ignored in your work is a sure recipe for making sure that your resistance is as low as it can be. The fact that we are both ill is an indication of the stress of a decade of struggle, trying to be honest and fair and do what is right. It is an indictment of this clean, green, 'friendly' country.

Some of what I have written will sound quite bitter and sad to many. No doubt it is. That is what rejection does. It does not render our feelings invalid. But that is how I felt, and feelings and the mind are powerful forces for good or harm.

Over the last couple of years my relations with my parents have become warmer as they finally seemed to understand how we are struggling. At first they just seemed to be totally critical of what we are trying to do because we never have any money and live in chaos. Now, as they have moved into a retirement village and the strain has come off them and also as they realise the seriousness of my situation, they have become quite concerned and helpful. I just wish they lived closer. They used to be only half an hour away and I could drop in. But on reflection, even then I saw little of them. They had such busy lives doing things that mean little to us and sadly, I got to know none of their friends or their children which could have helped my integration into life in Auckland. I felt very isolated. But now I hardly see them, though we do keep in touch by phone.

My early life was peppered by separations from my mother as she had a lot of illness, culminating with polio when I was about four years old. I also became ill. My traumatic experiences, alone and isolated in Auckland Hospital at that time while my mother was critically ill in another part of the hospital have haunted me to this day. I still get panic attacks there. All cancer treatment is done at Auckland Hospital and I just cannot go there, especially isolated, as you have to be for the radiation treatment. All my memories are of my mother being taken away in an ambulance, separations, feeling

abandoned, frightened and alone. It still affects me deeply. Once after a procedure in 1998, I collapsed in the foyer of Auckland Hospital when Brian had gone to get the car. He returned to find that I had been rushed down to Emergency.

The effects of my early years were clear in the therapeutic relationship I had with Simon, a young doctor who recognised my problems and tried to help. Unfortunately, while we were making progress, just at a critical time, he went into another branch of medicine and I lost a vital support. I was just about coping with this when my cancer was diagnosed. I so needed that outside support and someone to talk to. Only a couple of months before losing Simon, I had also lost my mental health counsellor, too, as she was moved to another area.

So, all in all, I was pretty bereft at what was a critical time for me. But perhaps it was God's way to force me to stand on my own and weigh everything up. And I have coped! I am very proud of that. It is something I have actually achieved by my own effort, despite everything.

I have suffered all my life with feeling I am not good enough. This was the message which seemed to come through loud and clear from my parents, even though, I am sure, they didn't intend it. Nor have they approved of either of my husbands and it would seem that this one is much worse than the last.

It was not until I came back that I realised how authoritarian New Zealand is and now I can see this influence in my early life. My parents were the personification of this New Zealand culture. I can see that now. I have shadowy memories and fears dating from way back which still affect me, maybe to do with all the separations. I am sure that there was no lack of caring on the part of my parents, who no doubt did their best through illness and difficulties. All of us who are parents try to do this. I lay no blame anywhere. But whatever happened,

circumstances seem to have conspired to make me fearful and afraid. I am even made to doubt my own memories. However, my reactions seem to indicate some deep childhood feelings with which I have never come to terms.

Recently I came across a quote in Dr. Andrew Lockie's *The Family Guide to Homeopathy*, a quote which I found very relevant, given the psychological problems I have:

For years psychologists have been pointing out that there is a 'cancer personality', rooted in unresolved conflict between mother and child; typically the child deals with his or her frustration by becoming too adult too soon, by repudiating affection and denying his or her own needs. Sooner or later these unsatisfied needs reassert themselves, usually as the result of the loss of a loved object or person. Though cancer is not the only expression of buried needs, diagnoses of cancer in people who have lost a close relative or friend within the previous 18 months are well above chance. It should also be said that the age-cancer link may have something to do with the generally low esteem in which old people are held in our society.

So, the seeds of cancer were probably there from my earliest childhood. However, there is no blame, but just a situation which existed and my somewhat unsuccessful struggle to adjust. And now on my return home, I do not feel any sense of self-esteem, only rejection and failure.

My husband, Brian, has been my help and my guide through all of this trauma. I just couldn't be without him and it pains me terribly to think that he might have to be without me. He would have nothing then - in this world. However, because of the extreme stress that he has been under here, I have found it difficult to talk to him freely about all of these emotions. I do not wish to hurt him. He said that even the thought of reading my book made him feel very low. He knows

how much I have tried and he fears I may be losing the battle.

I care so very much about him and it has almost destroyed me watching him slowly dying before my eyes. He has become more and more disheartened by the empty life here, the sly attacks on him professionally, the lack of competence he finds all around, and his inability to get anywhere with what really matters to him, that is, the publicising of his scientific proof of the existence of God. One of the reasons I chose not to have radical treatment was that I felt that I could last longer and be of more help to him if I followed the guidance we both get. I did not feel I would live if I had surgery.

So, I had lost 'my little corner of England' as I used to call my home in Epsom, Surrey. I had lost the richness and real culture of a country where you could feel the countless feet that had walked there through the centuries and the easy proximity to even older cultures. I had already lost my home here as the land to which I had returned was no longer a safe or welcoming place. I felt I had lost my family and had no friends. I felt I was losing my husband as he lost heart. I lost what little sense I had of my own value as I was made to feel unacceptable, told to go home. After 20 years of life abroad, I do not have a New Zealand accent. Perhaps I never did. They assumed I must be English because I was critical.

And in a way, England is now more home. Although it has become more '1984' since I left in 1995, there I was never made to feel unwelcome as I am here, in my birth country. That really is an indictment of this green and unpleasant land. I had lost all heart and all desire to live. What a recipe for a serious illness! And that was the fertile ground in which my cancer grew.

But enough of depression! I am still alive, still fighting strongly. That has got to be a good thing. I feel much more at peace with

myself, much calmer and stronger. I appreciate the time I have left and just trust God that I have the time to do what I need to do.

This book is compiled from writings over the period from when I first had an inkling about my cancer. The book was originally put together in 36 hours from what I had written as a journal. It was for an entry in a literary competition on the subject of Mind, Body, Spirit. Unfortunately, a misunderstanding meant that it was never judged. However, it was the spur to setting down my story. I have added explanatory footnotes and introductory or final sections to the original writings which are in italics. These notes are written with hindsight and are more rational than the raw emotion that comes out in the original writing.

But cancer is an emotional subject. The myriad emotions that swirl and jostle for space are almost too much to catch hold of. This is an attempt to show how you can touch each of these emotions and feel them change from fear and confusion to more positive feelings. It is important to feel and then let go. Only in this is there the freedom to move on and use the remaining time, hopefully to fulfil your destiny.

Although cancer may bring about the end of my life, perhaps it has freed me to be able to find myself. So maybe it is my destiny. It has certainly allowed me the freedom to speak up for myself for the first time in my life.

Perhaps cancer is not just the evil killer that the medical profession seem to imply when they offer to save your life. At best, they can only defer your death. But that phrase does not cast them as saviours. A radiologist said to me, "There's no guarantee you'd be any better off today, even with conventional treatment" - and that at least is honest.

It is probably that everything has a purpose which only God knows. Maybe in time, we can come to understand part of

A Cancer Journey

His purpose. One thing I do know is that I am grateful to have had this opportunity to understand and become stronger. For me, cancer has been a positive force, no matter what the eventual outcome.

I sincerely hope that, by giving an insight into this process, with all its attendant emotions, others in a similar situation may be helped to understand the normality of their own reactions and look beyond the easy guarantees of the medical profession. Above all, I hope that they can come closer to that seat of knowing deep within each one of us, the soul. For it is the soul which will go on when the mortal struggle is done and it is through the soul that we can truly communicate with God and find our destiny.

30th September 2004

A CANCER JOURNEY

PART I

DILEMMAS AND DECISIONS

That C Diagnosis!



It was 6th September, 2000, not long after nine in the morning. The phone rang. It was the gynaecologist's nurse. "Your cone biopsy results have come back and Andrew would like you to come in with Brian to discuss them. Can you make 2.30 this afternoon?" That sounded really ominous. If the results were OK then why did he need me to go in and discuss them? There was obviously something badly wrong. Their psychology is badly flawed.

I had to go to Pukekohe, some fifteen miles away, and pay the wages that day at the gym where I did the accounts. Usually I went in the afternoon but somehow I knew I wouldn't be in any fit state to go after my appointment at Ascot Hospital. I just about had time for the half hour drive each way, to get all the work done, then have a few minutes for a light lunch. At least it would take my mind off things if I kept busy before that dreaded visit.

Dashing through my work as I was pressed for time, I was bothered by the continual interruption of the Manageress who was having problems with her teenage son. He had been suspended from school for some serious misdemeanour and was now in the office I shared with his mother. I really couldn't concentrate. Then there was a phone call for me. It was a Papakura GP's nurse, telling me my smear results had come

back. I could hardly hear what she was saying over the arguments but then I realised she was telling me that it looked like invasive cancer! Wow! I had only prepared myself for micro-invasion - Where the cancer cells haven't penetrated further than the very top layer of the skin.

My regular GP had refused to send in another smear before the biopsy, saying I would probably back out of having the cone if the results were OK. I didn't trust the lab results in the light of my experience. So I had dashed around on the morning of my cone biopsy, trying to find a local doctor who would take a routine smear for comparison purposes, as a vaguely scientific test of smear tests, I suppose. However, this doctor, being PC, had also put on the form that I was having the cone biopsy and so the whole point of the independent test was lost. Still, she had got to keep her nose clean.

I had asked that the results be faxed to my home so I had them for my visit to my gynaecologist but the nurse wouldn't do that without first speaking to me because of the nature of the findings. It was difficult for me to take in and the upset and loud conversations in the office were no help. I'd have preferred the fax in the privacy of my own home, with my husband there for support, not a phone call in the chaos of the office, which was much worse than usual that day. But they always know best and the medical profession, so concerned with sensitivity and professionalism, is all PC.

Then when I thought about it, it was so much worse. It was not important enough for the doctor to have told me herself, rather than just having her nurse phone me. And they say women doctors are more empathic, have more feeling! I don't think so! She was so keen to follow procedures. I should have just gone in and given a false name. Then only I would have been able to correlate the latest smear with the colposcopy (a colposcopy is an examination with a fancy pair of binoculars

while the woman is strung up inelegantly). A careful inspection can be made and biopsy taken of any suspicious area. The laboratory would not have had the opportunity to make the results fit. But her first duty lay to the professionals, rather than to help me as a patient, a patient who had already been betrayed so badly by that particular profession. Only later did I smell a rat. Could they really tell that from the smears? Or was it more evidence of the crooked system. It seemed remarkable to me that the smear, taken first, was reported after the biopsy and that it all so neatly fitted with my records, available to those doing the testing. But I was unable to get anything retested. Whose samples were they, anyway?

I tried to phone my husband at home to tell him and to ask him to retrieve the fax. The Manageress was hogging the phone with her problems with her wretched son. Eventually, I managed to let her know I really needed to make a call. However, Brian must have been in the workshop where he couldn't hear the phone. He didn't notice the little tell-tale light, the sign of my new message on the answerphone. So, when I arrived home, he was not forewarned. And I had had nobody to discuss it with. This was not the best start to my ordeal. It had been a tragedy of errors from the very start. And it only got much worse!

Brian drove me into Auckland. I was really in a bit of a daze. Thoughts raced through my mind. Suddenly I saw the clouds - big, white, fluffy cumulous clouds. They seemed to billow above us. The previous evening, we had been looking at some books about the artist John Constable and how he spent hours just practising drawing clouds on Hampstead Heath in London, trying to capture all their nuances. I commented to Brian that these were 'Constable clouds'. Then I came out with something

strange. Will I be like a cloud, do you think? Already, my anxiety was causing me to think about dying. There was a short wait for the doctor, during which Brian tried in vain to restart my watch which had suddenly just stopped! Was this time standing still? Time stopping for me? Was this the finish? My old time was certainly stopping. A new and different time was to begin.

At least the gynaecologist didn't try to beat about the bush. He went straight to the point.

"I'm sorry. It's invasive cancer."

How many people have heard these dreaded words? And how do they react? Anger, tears, denial, arguing, shock? Or is it all of these?

Shock and Grief



This is how it all began. On first hearing about the first high grade cervical smear result, the one which led to the diagnosis of cancer, I had sat at my computer and tried to make sense of it all. Things seemed to have moved at a terrible swift pace, far too fast for my understanding.

It had all only come about now through chance, a chain of events anchored in the lab's incompetence. I had had a routine smear test done in May 2000. However, the laboratory managed to lose the specimen and discovered that they only had the form which, en route, had parted company with the sample.

When next I had visited the GP he informed me of this. Brian, an analytical chemist, was becoming progressively more angry at the shambles of the medical testing system. He wondered scathingly whether anyone labels samples in the medical system. Where was the sample with that form? Anyway, it was probably a blessing in disguise as the laboratory had said they would do a smear for free to make up for it. As a result, my GP had done a thin prep smear, using a process which apparently is more accurate but is much more expensive so is not normally offered. You have to specifically ask. I didn't even know about it. As usual, everything comes down to a price. Nobody tells you that they are selling you a cheap test which is unreliable and you can pay more for better advice, although to

be fair, my doctor was in a very poor area.

This smear had shown ASCUS. (This is Abnormal Squamous Cells of Uncertain Significance where they can see unusual cells but don't really know what they are). I was not unduly concerned although I had had a bit of unusual bleeding back in April. In a way, it seemed almost right to have a smear show some abnormality as I had been concerned about five clear smears since being in New Zealand. I couldn't see why they should be clear because I had only recently found out that my smear results had been CIN-II in England five years before and although I felt they could have changed a bit, they would surely not have gone down two grades! But no one told me then or explained the significance. It emerged only when Brian managed, with difficulty, to get our medical notes in 1998, following a visit back to England. In fact, on going through these records while writing this, I discovered that, even in 1987, I had CIN-III, but I was not advised of this or the need for another smear. I didn't have another one until 1990. (The English GP system insisted that you were registered with one GP. I didn't like mine and ended up in tears every time I visited him. Once, when I had gone to him with the girls, aged about 5 and 2, for a hepatitis injection, he had speared them in the leg then dismissed us. All three of us fainted and I had to drag the girls onto a fire escape to recover in the fresh air. When I tried to change doctors, I was blocked. This doctor was the one who didn't recall me. He had also destroyed almost all my notes before he retired, so there was little except for a few hospital letters. I was distressed as I had been on Progesterone injections to hold on to my second baby and he was the company doctor. I was unable to find out what I had been given or whether it might have affected my daughter. It strikes me as negligence, but the records have gone.

But by the time I found out about any problems, all my

annual smear tests in New Zealand were clear, so I wasn't sure what to make of it.

The screening laboratory had now recommended using oestrogen cream then having a follow-up smear. This helps show up the difference in cells, apparently. It also feeds a cancer, I later discovered. I wasn't happy about this approach as I had always had an oestrogen/progesterone imbalance, but I did as advised. However, things only got worse. Later I discovered that I had been prescribed double the normal dose. Now this third smear test in a matter of a couple of months had come back with results worrying to my GP.

The concerns and emotions swirled around inside me as I tried to take in the implications of this news. I really needed someone independent to talk to, someone who knew me and the fears which already beset me, and who also had some understanding of this new problem. I was shocked at the rapid progression and couldn't understand it. It seemed easier just to give up and die quickly if that was to be my fate.

It had been a really tough year. I had become very depressed since being back home in New Zealand and had eventually been referred for counselling at the local mental health clinic. I was fortunate to be allocated a counsellor, Marianne, who could understand my feelings about New Zealand as she, too, had suffered rejection here as a child from South Africa. We did a lot of work together and I was making progress when my therapy was terminated just before Marianne was transferred to another clinic. There is the system, as usual, at its best. Musical jobs, as Brian used to call it in his Water Authority days.

I had also met Simon, a young doctor from the local Accident and Emergency clinic who had been helping me with my emotional problems, particularly the 'freezing', for several years. This is a defence mechanism whereby I 'switch out' in

fear and stress, being unable to communicate, almost unresponsive, even though sometimes I am aware, to some extent, of what is happening around me. I appear to be unconscious, with just a flicker of life. It is quite terrifying, as I am helpless.

On a few occasions in recent years, I had ended up in an ambulance. Once it was at the shops and another time, Brian had to be summoned from Tauranga. I think it is just a defence mechanism, some pathway established in childhood, a sort of overload cut-out switch to counter some traumatic experience – but what? I don't know, but for a variety of reasons, I have my suspicions. This makes life difficult and I have spent a long time trying to overcome it. It is quite scary, in fact. Simon was helping me to reach into that fear.

Simon was interested in coincidence as well, and so had got on well with Brian as this was a field in which we had been working since 1988. It is a difficult field as nobody takes it seriously. However, we have had some interesting scientific results.

Simon made time for me, without charge, and was learning from me as a patient. He had hoped to be able to specialise in psychiatry. This concern was a very welcome change from the brutal, market forces, user-pays of the New Zealand of today. Was that another example of meaningful coincidence? I was led to someone who really could help me, who was interested, instead of my having to pay a psychologist \$150 an hour for platitudes. But did I mess it up because of my own fears and needs?

I was quite happy that he should learn from his experience with me. It was a two-way clinical relationship which had benefits for us both. He said that he gained in his professional understanding of patients from his meetings with me. However, as the inevitable transference occurred, it became more and

more difficult for me to sort out my feelings about being back in New Zealand and my pain at the way Brian had been professionally rejected here. Simon knew me better than anyone else apart from Brian. (Transference is where, as trust builds, the patient transmits his or her past emotional attachments to the psychoanalyst so that the analyst is a substitute for the parental figure. This seems to be one of the basic principles of psycho-analytic treatment. As treatment progresses and understanding is gained, this transference needs to be dissolved so that the patient can reassert his independence and resume an adult role. Dissolution can prove difficult in some cases, especially if the timing is not right. There is also 'counter-transference' where the therapist can transfer his own feelings from the past into his relationship with the patient. Such feelings have to be recognised and overcome).

Unfortunately, just at a critical time in the treatment, he made a move into a completely different field of medicine, shifted away from Papakura and disappeared from my life. For a time he kept a house here and called in very occasionally. He did try to let me down gently but it was still a terrible blow to me, especially as it was at a fairly critical point in resolving my problems. What was worse, it came very soon after Marianne had been moved on to a different area. I was very much alone. I now really did have no one to talk to.

My chats with Simon had been such an important part of my life in trying to come to terms with the way these different emotions from past and present New Zealand were affecting me. He had acted as a psychologist, I suppose, but a friendly one, not a 'trained' one. Perhaps for this reason I could not separate out my feelings and what was happening and had happened in my life and the need to be able to come to terms with these feelings through talking about them. I suppose, above all, I needed acceptance. And the worst place for anyone

who really needs that is New Zealand.

There was this sad realisation of what had formed me and how my native land really was towards foreigners. I had found our talks a little like looking at things reflected back at me more objectively in the mirror of another person. But now, like Marianne, Simon had gone.

I tried to explain to Brian the complex transference problems which had begun to arise but he refused to accept this concept, although he did accept that something serious had happened to me as a child. What he did not believe was that psychiatry would solve my problems. He has no time for psychologists or psychiatrists because of their blinkered attitude to the paranormal and the reality of life after death. Also he had had very bad experiences of them with his ex-wife and daughter. I suppose I was trying to convince him of anything in their language – jargon he calls it. He concluded I had an infatuation. My closeness to Simon hurt him so I couldn't discuss my loss with him. It may well have looked and sounded that Brian was right. I was certainly very dependent on Simon and he left at a critical time in my trying to resolve the problems of my past.

Looking back, I can see I was grieving for this loss of support. Then I was hit with this sudden cancer diagnosis. It was so difficult all at once. Just when I most needed outside support, it had all gone. Both Marianne and Simon had gone inside nine months prior to my diagnosis.

However, in time I came to wonder whether this was to force me to stand on my own two feet. Was it all somehow orchestrated to help me, in a strange roundabout way? But now I just felt despair. I was effectively grieving for so many things while trying to carry on as normal. Something had to give. And it looks as if it was my immune system. Was this why I developed cancer?

Overwhelmed – It's All Too Much



I have included this chapter from the notes I made at the time because it does emphasise this whirlpool of emotions, some of which are to do with my cancer and some to do with my emotional struggles at being back in New Zealand - my homesickness for the English countryside, for culture and for the feeling there of depth, of England's past, yet a timelessness. Perhaps I could feel the spirits of those who had gone before.

Cancer often seems to land in a life which is already in a disrupted state. It does not happen in isolation, but on top of a lot of other complications..... I apologise to the reader who finds it a bit confused or intense, but this is what was happening in the period leading up to my diagnosis. My emotions were up and down as I tried to work through my loneliness and grief as well as deal with a depressed and disillusioned husband. There seemed nowhere I could turn.

This is as I wrote it at the time, complete, almost all one night, trying to make sense, trying not to feel the pain of my aloneness and my total loss of support.

Sunday, 30th July 2000 5 pm - The First
Inklings of a Problem

I thought I had got it all under control - but no! I am so weepy today and I'm not sure what is the main reason. Friday afternoon I got home from my new job at the gym to an answerphone message from my GP about my smear test which I had had to have repeated after using oestrogen. This was the third test as the lab lost my first one. It had gone from CIN-I to CIN-III in two weeks and he was most anxious to pack me off for a colposcopy. Surely it can't have changed that much in two weeks?? But then I had to use the oestrogen so perhaps that has had some bad effect. I have always been against it. Anyway, I am frightened as this is the second time I have had to go for laser treatment and this time my GP reckons I may have to have worse! And it is bound up with such a sensitive emotional area too. I almost didn't manage the last smear test as I find the left lateral position terrifying. I have no control and cannot see the doctor's face; it created a very deep fear and I just froze. I didn't completely 'disappear' but I did switch out though. I felt vulnerable. That seems to have got worse of late.

So, all that didn't do much for me on Friday, especially as I can't get a gynae appointment for a week and then nothing can be done for two weeks after that - or more likely a month because of my cycle. Brian reckons that one of the tests must be wrong, that surely there couldn't be that much change? I have been suspicious of my negative results for a long time as I had positive results in

England. But I didn't find out until I managed to get hold of my notes from England several years after coming to New Zealand when Brian made a trip back in 1996/7. Here in New Zealand all my results have been negative for five years. I thought the English ones were wrong, how wrong could I be? But why was it different? And there had been occasional bleeding problems over the years 1997-8 but the gynae had just muttered about the menopause and tried to put me on hormone replacement therapy while denying that was what it was. I was not impressed. It didn't seem honest.

Now, suddenly, it has swung to a more serious level. Even when I had the laser treatment in England, it was only CIN-II, as I had now found out. But they had made out it was nothing, no worse than having a wart cauterised. Even there, they had not been entirely honest. Why do the doctors, in their infinite wisdom, always have to shield you from the truth? I would rather know but I had not been told. It is probably in part to hide the fact that they don't know or are unsure themselves. So I was not at all bothered until I got hold of my notes from England and, on reading them, wondered if there may still be a problem, even though smears here showed normal. I had tried to point it out to my GP and my gynaecologist, to no avail. I don't think they bothered to read the notes I photocopied for them.

I was to find out it was all part of the standard medical technique of gradual disclosure. You tell the patient as little as you possibly can, to avoid alarm. I suddenly understood this when I read John Diamond's Book 'C'. On page 63 he discusses

this: *'The principle is simple and at first glance makes a certain sort of sense. In the case of complicated, possibly fatal and emotionally charged illness, never tell the patient more than he is likely to find out for himself, and only ever give the best-case scenario. Thus when we first talked about radiotherapy, we were talking about a simple procedure with very few side-effects. When we were discussing occult sites for my primary tumour, we were considering a place which almost certainly would not exist after the radiotherapy. When, some months along the line, the subject of surgery came up, it was an in-and-out snip-snip sort of surgery. But the radiotherapy turned out to have a mass of side-effects and would lead to eight hours of major surgery.'*

So, I'm scared and confused and feel very betrayed by the British system, but especially by the New Zealand one. It is so ironic that there is the upset at present about the misreading of smear tests in Gisborne and all those women who thought they were clear who have now got invasive cancer. *In spite of this and my concerns, my GP just kept telling me, "Jenny, we have got the best labs in the world." I got nowhere until suddenly it was proved that they were not the best.*

But they make out it is just one doctor responsible, at Gisborne, an isolated area. My experience shows that it is not, but who cares?

I had hoped Simon might call in, even though he hadn't confirmed he was coming up. I really needed to talk to someone who knew me and was independent. I didn't want to worry Brian, and Simon could perhaps give me some medical answers. His parents were at his house so that was perhaps a positive sign. I had noticed that when I drove past on

Wednesday night on my way to do the wages at the gym.

Just after that, I had to stop to pick up a just-killed cat off the road on the bad bend just past the Opaheke railway level crossing. I am sure it was the car that came towards me on the crossing that got him. He looked just like old an old, stray, tabby tomcat I had taken in and looked after called Silver and I remembered how he looked when he had been hit by a car. This one's pupils hadn't yet fully dilated when I got to him so he wasn't quite dead - but so close it didn't matter. It didn't do much for that day either, so close on Sooty's death. Death was not something I wished to contemplate much, though it now seemed a lot closer.

Anyway, not unexpectedly, Simon hadn't come. Nor had he contacted me, in spite of my letter. I know he has probably been away. I keep trying to rationalise it. But it comes down to him not caring enough at all. Yet he wrote a week or so ago. I can't understand it. And it hurts and confuses me. I know I had got too dependent and that was dangerous. I suppose I am still grieving for my loss, although I am pleased that he appears to be relishing his new job.

Trouble was that my parents were also coming this weekend - up in Auckland for a few days before yet another holiday, this time in Singapore, with some wealthy friends. They never do much for me or my mood as they are always so critical of the way I live. We have totally opposing philosophies of life. This time was even worse. Usually I try to clear up to avoid too many sarcastic comments. However, Brian was trying to find somewhere for the huge piles of

books and papers in the hallway. We have so little room for all our books and equipment. They can waste money on holidays but we get nothing but sarcasm about our work and interests, and the fact that our place always looks a shambles because of the ongoing research work, not enough time and nobody to help. It is utterly disheartening. I suppose, in some ways, I would be happier living a 'normal' professional life rather than living on the fringes because of doing unorthodox work. This means we never have any money and even if we do take a holiday, it is always part of our work. And if you haven't got lots of money, you are doubly unworthy. I suppose I was envious and wishing they could understand. Brian reckons he is the worst person I could be with. I need acknowledgement and he doubts he will get it in what matters now, so that reflects on me too. He said he was acknowledged for being the best so often in his life, at least until he came to New Zealand – a scholarship to Grammar School then another to Oxford, a First, a D.Phil, rapid promotion in the water authority, at least until he got to the level where saying the right thing mattered more than doing it. I have never ever had any acknowledgement in anything from the world. I suppose that's why something at least from my parents, even from Simon, mattered so much to me.

I didn't want to make any sort of mention about Simon possibly coming, especially as I felt in my heart that he wouldn't. I didn't want problems with Brian, either being annoyed at me for wanting to see Simon or by making sarcastic comments about my being let down when he didn't arrive. He feels a bit

threatened that I seem to need to talk to Simon. I can understand that but I was finding it very difficult to talk to Brian as he was wrapped up in his unhappiness with life in New Zealand and now his worry about me. So, I just got on with things slowly and methodically on Friday night, and again on Saturday.

By Saturday, the depression had really set in and I felt weepy and clingy and so wasn't very effective. My parents arrived earlier than anticipated - they must have driven very fast from Hawke's Bay, without a break. So, I was caught on the hop with boxes still lying around. And, to make things worse, I had left a door open and a stray tom cat had come in and peed on a pile of papers and I couldn't shift the stink. They both hate cats so they were pretty sarcastic.

So, as usual, I found myself wrong-footed with them, on the defensive. And as usual they refused even a cup of tea and could barely bring themselves to stay a bit. No wonder with the stink. But I make such a huge effort when they come. Then I got it in the neck because my younger daughter, Miranda, still hasn't sent them a thank-you letter for her wedding present. It is typical of her. She always means well but she is so involved with her cattery which uses up so much of her time. It doesn't make a lot of money so she struggles to keep her head above water. I get cross with her at not getting round to things but I love her dearly and she is great company. Still, I had to agree with my parents about her manners. I despair.

And then for conversation, as usual, again I got all the spiel about how wonderful all my mother's friends' daughters are - such lovely girls, doing so

well (in their own rights) as well as being married to such successful professionals or businessmen. And they all have such wonderful children who are all doing so well too. I really can't stand it. It's all hypocrisy. The implication is that I have not married well and have wasted my life. The fact that I am not wealthy and living in a good area says it all. They show little understanding of us or what we do manage to do. Brian showed Dad his work in the garage. My father has a respect for what Brian can do on the practical front as he knows how hard some of it is and can appreciate workmanship. Mum just looks and makes little comment. It hurts because I am proud of what my husband can do. And whatever he does, he does well and with precision. He is quite talented and thorough, unlike the 'she'll be right' attitudes so often seen.

I had wanted to show them and have them understand. I had wanted to talk to my father but he never stays long enough. I had wanted to show Simon what we had done too. Simon just makes the things with my parents seem even worse. I feel betrayed on both fronts because he increases the hurt. Especially this weekend when they were both expected together, it made it seem even more obvious and I was desperately trying not to let my depression show as my parents don't accept depression. Everyone should be strong, like them

And I have been weepy. There is the soldier who was killed in East Timor where Simon was about to go. My father was rather scathing about all the fuss. He saw his mates killed all around him and was wounded himself. He said what would have happened if they

did that for every one of them that was killed during World War II? I can understand that. But he didn't know of my personal concern.

And, of course, it was the day after my brother Pete's birthday and that is always a raw time for them. But I tried to talk to my mother about Mt Hobson where his ashes are buried. However, she just brushed me aside. I feel useless because I am not what they want. I am not Peter. I am not rich and I am not successful. We have spent everything we have on our paranormal research work as it is the most important thing to us. We know our work is valid and it forms the basis for our proof of the existence of God. Following the signs is how I made my decisions about my cancer. And, worst of all, I have a moralistic outlook on life and am critical, especially of those desperate to climb the slippery pole by whatever means, whatever the ultimate cost either to themselves or to others.

I just cannot stop crying. It just gets worse. If Simon had called in, I know it would have been joyous. That would have overridden the other things. Last time, in spite of all the hassle with Brian, I felt really good because few people call in here and it makes something different in life. That feeling, that perhaps there was someone else who cared, has lasted right up to this weekend. As it is, Simon's lack of communication has just intensified the pain from the other things. I am at the point now where I want to die. Yet, there are so many things I want to do. And I am overwhelmed.

I have to go and make the marmalade now. The oranges Brian was given have hung round on the

kitchen floor in a plastic bag and are starting to go off so I have to do something. But that is just one more thing to add to the list. And I really just don't care.

My emotions were swinging wildly. I needed some stabilising influence. I couldn't talk to Brian easily. He was too close and too involved and I didn't want to increase his worry and pain at perhaps losing me. He would not only be losing his wife and companion, but the only person who has ever bothered to help him in what he is trying to do, the one person who is willing to help him. Life had to continue as normally as possible. My moods seemed to be see-sawing. I was shredded into little pieces inside, one minute feeling confident and the next as if my world was ending. I was desperate for someone to talk to, someone who could understand, but both Marianne and Simon had disappeared and I didn't want to worry Brian.

I couldn't really talk to my parents as they didn't really understand my feelings about the situation we were in. They couldn't understand and didn't want to hear about the pain of my realising that the country of my birth and my childhood, the country I had loved and considered home during all those years as an expatriate, was so stifling and shallow, so unaccepting of anything different. I had come to realise what an authoritarian society New Zealand is and that we were trapped. At no time when I was living in England did I ever have this feeling of being despised for being different or a foreigner. There I had been really accepted and welcomed. Here, because of not having a strong New Zealand accent, I am told "Go back to where you came from!" All these feelings were swirling round inside, along with the guilt that what I had once felt was my country could be so cruel to immigrants. What really horrible people my compatriots were! And to think that I am supposed

to be one of them! Was it the five years of these stresses which had finally been enough to finally provoke this cancer?

I needed to talk to someone who understood. Gradually, though, I managed to break down the barriers with Brian and feel more able to let him help me. And that had to be a good thing!

Can't Communicate



Sunday, 30th July 2000 - 10.15 pm

Well, I made the effort and cooked up eight large jars of marmalade. It could have set slightly more but I guess it will be OK. Watched Montana Sunday Theatre while I did all the ironing. It was about a tour bus driver going all round England. I realised how homesick I still am for England. I was thinking about Dover today. I feel so sad most of the time. I love NZ but can't seem to relate to it any more and my parents don't help much. I feel helpless in a situation which I find soul-destroying. Almost all change is for the worse and there is nothing I can do. I often wonder if I really want to keep on going.

But yet I do. There is so much I want to do. I found my mouth organ yesterday when I was clearing up and just sat and played all sorts of tunes, from Scottish and Irish ballads to hymns. Sometimes it was sad and lilting; then joyous tunes. I just made them up. I enjoy composing. Then I found my chromatic mouth organ. It is not as easy to play for general composing but gives a much cleaner sound and I can get the half notes.

My daughter Miranda (Ran) was talking the

other day and going on about a friend of hers about my age who likes to give her things and do things for her. Ran then gets angry as this friend then expects an acknowledgement, which is not unreasonable. But as Ran says, she did not ask for the things, and it is a hassle to respond. That seems selfish to me. But she hates the responsibility of someone else's expectation. That's where she differs from me. She can just cut it off, whereas I suffer terribly from guilt.

I like to give too. I love to give Ran little surprises and she doesn't find difficulty in responding to those because there is no pressure or expectation. I like to give to my parents too - but they just won't accept anything. I always feel terrible, no matter what I try to do for them. It seems to be just thrown back at me or totally ignored. They won't even accept a cup of tea. I don't think they realise how important it is to accept things graciously. It makes people feel good to give and rejected if their gift is not accepted. Accepting something from someone is a form of acknowledgement. It shows grace.

I feel isolated. Life is pretty lonely.

I am so glad Brian is here for me. That sounds terrible, as though I have to have someone to lean on. I suppose I do, in a way. However, he does respond and I do so love him. And even if he has got short tempered because of his utter frustration with life here or been harsh with me, he does realise and try to meet my needs. And I try to meet his. I understand him and love him and want to help him. And he is the same with me. He keeps saying that I have a difficult life because of him and that he is probably the reason I'm not happy. In some ways it

is. But mostly, I am happy that I am sharing his life, helping him to do what we both feel is right. I just get so frustrated as I cannot do all the things I need to. I feel exhausted so much of the time and overwhelmed with the volume of things I try to do. And now this latest problem, coming on top of the triple therapy (for helicobacter infection), etc. has really knocked me so that I am not functioning as I was. But Brian is being very understanding - on the whole.

Tomorrow I will try to make the time to start on my gym programme. That might make me feel a bit better - I don't know. I seem to have lost the heart for it now that I have the smear test news. I just don't feel as if there is any point. I know that it is not all that serious, but it is just that all the false negatives kept coming back and I knew, deep down, they were wrong and I kept feeling insecure about them. And then, suddenly, it is much worse than my GP thought when these results came back. Or worse, if I have to have bits cut out! I am only just hanging onto myself over my failure to get pregnant and my imminent total loss of fertility. Even though it was totally illogical and I probably would have been too tired to manage, I still hankered after another baby. I had had a bad experience with my first daughter's birth and then struggled to have a second baby. Each month has seemed a bonus - and now this!! The doctor said to go and talk to him about it this week. I don't know when I can as it is a ridiculously full week.

I feel I would like to talk it out with someone. My GP cannot understand all the underneath elements

of my fears about it. He is reasonably patient when I 'freeze' for a smear test or examination, but he just cannot understand and I don't want to make his job harder. I don't want to keep on crying like this. I am just not functioning again. And I cannot afford for it to be like this. I enjoy this job and don't want to lose it. And tonight I must write to get out of jury service again. I just can't cope with that as well at the moment. They are hassling me. I have been called up twice in two months. I just can't do it.

I'll go and take Brian a cup of chocolate in the garage. He's making his humbucking machine for bookbinding. He is using a beautiful bit of hardwood we found in the woodshed. He gets a real kick out of bookbinding and making things like this with such care and precision. I do love him and don't want to be like this.

So many thoughts and feelings, only some of them relevant to my possible cancer.... But these were all the little details of life I was trying to keep going while adjusting to the fact that I may well have a terminal illness and that these little details may not exist for me in the future. It was a sobering thought. And all the while I was hurting emotionally and hoping I could patch up strained relationships. That was of utmost importance to me. I needed my family and friends so much.

Midnight.

I took the chocolate out. Brian is upset because his pillar drill is not set accurately from the factory. He has tried to make the work perfect, in his usual

manner, but this has caused a problem so that one of the holes was not true. Still, I think it looks pretty good. He is such a perfectionist, though, especially when making machines. Then I drafted a letter to the Courts as I really don't feel well enough to do Jury Service and I have been called up again. I am not getting much accomplished in my work here tonight as I feel so low.

It is hard. Everywhere I go in the garden there is a reminder of pain. I made up three hanging baskets today and put them outside the study. But I couldn't hang one on the kowhai tree as it leans the wrong way. It causes me pain every time I look at that tree because that day that Simon helped Brian cut off the dead branches with his chainsaw, I saw how good it was to see Brian working at a mutual project with another man. The company was good for him as he is always so isolated. I had hoped this male friendship would continue but the week after that, in our regular session, Simon told me he was leaving. He tried to let me down gently but it was a shock, especially after my pleasure at seeing Brian have his company.

Everything is a reminder and causes me pain again. I guess I am still grieving. I thought I was over it. If only he would communicate! I feel like the bloke in that film *What Dreams May Come* trying to get through to his wife. Funny it was Simon who told us about that film and said we would probably be interested as he had loved it and it was about life after death and communication from the dead, a subject on which Brian and I have done a lot of work.

I just cannot do it. I thought I was better, but now I don't think I will ever forget or fully let go. I

cannot ever remember feeling like this in the past.

The worst thing is that I cannot talk about it with anyone. I am so alone in my pain and confusion. I cannot talk to Brian as it would hurt him and it would just increase his irritation at Simon and make him angry that I was hurt by him. And he warned me that what I was doing was harmful, but I ignored him. And now I am being hurt. Surely, too, it is wrong for me to have this attachment? I don't know. I didn't ask for it. It just happened. Simon said it was meant to happen, a transference, but that I should be able to get out of it in time. I just don't seem able to. Partly it is because I was not ready for him to go. The psychological work was only partly complete and was at a critical stage.

And now that he has gone, I cannot resolve the issues left, some of which have been made worse by being brought to the surface. I wish I could just spend an hour or so talking privately to him, trying to work through these issues. Or, I wish he could just respond in some way, let me know that he does understand, that these things are valid. But it is difficult for him to write to me as Brian will read the email and make comments. This is very inhibiting - a bit like having a medical consultation in front of a third party. Simon was my doctor and my friend and this is a difficult combination.

If he had just died or been killed, then in some ways that would have been easier. I would have been allowed to grieve. It would have been expected in a way. But I am expected to be grown up, strong, not have any feelings; just as I am expected not to be upset by my parents' unthinking treatment. I am

perhaps too sensitive. I don't know. They hurt me terribly. They probably don't even realise, but I can't explain to them without them rubbishing my feelings. They will never change. They will never understand because they don't want to.

And Simon will never change, he can never meet my needs. He doesn't want to. That is plain. I have remained loyal to him, defending him to Brian even though he hurts me terribly. I guess I will continue to do so. And he will continue to hurt me with his cavalier ways. However, I am grateful that he has started me on the hard road to recovery. But I have got bogged down along the way, entangled in emotions I find it so difficult to cope with. Is he still trying to make me strong? Or is he just being thoughtless? Does he want nothing more to do with me? I feel abandoned, just as I felt abandoned by my parents this weekend when I had needed their support and closeness. It is strange how Simon asked me to look at ways that he might be similar to my father as a way of resolving feelings about that. I had thought there wasn't any similarity, but now I can see lots of parallels.

And I am afraid. I don't think my father has much time left. He looked good, but I expect the worst. I am not sure if he will come back from this holiday. So, I am grieving for him, too, for the father-daughter relationship which went wrong. I want to retrieve it but he won't give me time. I can't bear it.

I want to die. But I don't want to abandon Brian. He would find it terribly difficult on his own. Life is not easy. We have nobody close now. However, having friends isn't everything. It would be nice,

though, to have someone outside I could trust.

So, I am alone with Brian once again. Maybe he is the only person I will ever be able to totally trust, who will never betray me. I hope I haven't betrayed him. Dying would be a betrayal, unless my life was taken by an illness. And even then, I should be strong enough to overcome it. I want to die in so many ways. Yet, when I look at what I want to accomplish, it seems a waste to die. But I don't know if I have the will to go on. It is so confusing and complicated. Dying would be the way out. But I must be stronger than that.

I need to make things right before either my father dies or I die. But I fear that that will never be. There is so much, too, I cannot say to Simon. Or I could say it as I could say things to my father, if only he would spare me the time without dashing off so that I feel abandoned. But with both, they would only half listen and I would be left feeling infinitely worse. Simon talked of transference of feelings and also asked me to see the ways in which he was similar to my father. Am I transferring my fears about my father and my insecurity onto him. But then, if I am, why? And what should be my proper feelings about Simon as Simon?

I just don't understand it but I need to - and quickly. If Simon had come this weekend, all this would not have reached a head. I was feeling quite good and strong, happy in my work, able to take the smear test results in my stride. And then, as all hope died over the weekend of Simon coming round or phoning, I have become more and more weepy. But I have to hide the true reason. At least I have the

other excuses which would have upset me anyway, but it would not have been nearly as bad as this. This is the worst I have been since February. Why am I so unstable?

I hate someone I trust having feet of clay but it always seems to happen. Simon will continue to let me down as long as he lives. I know that and must just somehow accept it, just as my parents have let me down, although unintentionally. Yet, I think back to little things they did for me. As I was making the jam, I remembered when I was at primary school and came home and announced that I had to make some fudge and coconut ice by the morning because I had entered the school competition in the Winter Show. Mum helped and supported me. She did all the practical things. But emotionally she just wasn't there.

Is Simon there emotionally but not in a practical sense? I just don't know. All I know is that I am hurting badly and can't stop crying. And I want to die. But that's too easy. So, I'll go to bed and pretend that I'm OK and try to pretend I'm not crying in the dark. I wish there was somewhere I could turn, some way I could understand, some way I could know. I cannot work Simon out. All I know is that I am hurting and confused. Will this ever end? Will I ever be strong enough? I must keep going! I must not give in. I will understand - one day.

Looking back from four years on, I can see clearly now how the feelings of depression, grief and abandonment, as well as feeling unsupported by friends and family most probably overwhelmed my immune system so any doubtful cells were not

able to be eliminated. This led to a sudden development of cancer which so commonly appears after a period of stress or a loss. I don't blame anyone but it shows I was not in control of my own life and my own body and mind. Over the years, I have come to understand this and now, yes, I am strong enough!

My first memories of my mother were of her being taken away in an ambulance and of her being in Auckland Hospital where I had the most horrendous experience as a 4 year old of being what felt like raped with all the doctors standing around, leaning over me, watching. And there was the total isolation as I was in an infectious ward. They even burnt my 'blue blanket' and the little Czechoslovakian dolls my grandmother had given me. I was so proud of those. I was totally alone and terrified. Then, coming back to Auckland brought all these memories back.

And then, of course, I lost both Marianne and then Simon. It was almost as if everything had been brought to a head, as if the cancer was meant to be. I tried to overcome my feelings from childhood which had been brought to the fore by my return to New Zealand and the loss of esteem both Brian and I felt here, but there was insufficient time before Simon left.

The psychological issues I had been working through with Simon gradually became less important as my system has gone into survival mode. However, at the time I wrote this, when I wasn't even sure if it was indeed cancer, things were pretty raw and obviously affecting me to a great degree. More than anything else, I needed someone independent I could trust. And I had lost this at a very critical time in my life. Four years or so later, I am over the grief and am strong enough to go back and look at that time in my life, learn from it and even laugh at it!

I now understand the emotional upheavals I went through in the past and set them out because they may strike a chord in the heart of others going through similar struggles, although

different people will be affected by different things. Separating the past from the present is a difficult thing to do, but can give an enormous understanding and ultimately, great strength.

I still feel isolated and have nobody to talk to about these things really. There are no cancer groups I can join as I am not taking the orthodox route. It is as though I have betrayed the sisterhood of those who have gone through the rituals of cancer treatment. I have not shared their experiences and they resent it that I have opted out. Perhaps they have a sneaking suspicion they should have done the same – but they were scared and awed by the doctors who told them they would die without their treatment.

Early Thoughts on Death and Dying



It all seemed too much. For the first time for several years, I had felt well enough to take a job, doing the accounts for a local gym. However, I was still missing Simon's support, even as a friend to talk to. Now everything seemed in jeopardy. I lapsed into a depression. There seemed no point in anything. I was wrestling with the problem of whether to have a cone biopsy or not. A large part of me felt it would exacerbate any cancer that may be there. Andrew had taken a punch biopsy at my visit on 4th August but commented as he examined me with a colposcope and obviously saw a lot of aceto-white, that he was unhappy and wanted to do a cone biopsy regardless. He wrote to my GP that he "hoped it wasn't worse than CIN-III". Aceto-white is a description of the abnormal tissue of the cervix after the whole area has been painted with a weak vinegar solution. The abnormal tissue shows up white in contrast to the pink of normal tissue. As it is acidic it does rather sting. But that pain disappeared quickly, in contrast to the mental anguish of what the test showed.

6th August 2000

I am trying to come to terms with death and dying. I

don't feel I will survive. I know it is illogical, as a high-grade problem with a smear test is not in itself life-threatening - only potentially. However, I have felt for a long time that something was wrong and that, in any case, for whatever reason, I do not have long.

It is a very vulnerable area emotionally for me. The only thing worse would have been my breast - but I'm not sure even about that. I had already said to my girls that I 'would die with all my bits'. This is bound up with so much pain and guilt and fear and confusion and unresolved feelings. It is to do with the very essence of me.

It is also bound up intimately with my parents and their attitude, their lack of protection of me when small and their response as I grew through childhood, leading to their lack of approval of me now as an adult. (It may not have been as bad as it sounds here in my scared and depressed state. However, that was how I felt. I had never been good enough and the child part of me was always crying out for them to appreciate me. My brother and sister and I all hated it that 'my little boys' seemed so much more important than us. My mother taught at Dilworth and got a lot of satisfaction from that, but we always felt left out. I do feel things are much better now and I enjoy their company at last.)

And then, even when I try to come to terms with that and free myself from it, Simon acts the same way and compounds the problems and the feelings. So I feel utterly alone - and this at a time when, more than ever, I need calm support and understanding.

I had trusted Simon, just as a small child trusts its parents. That was how the therapeutic

relationship was supposed to work. But he let me down in his most basic acknowledgement of me - where I am different. My parents could not cope with my difference, my individuality, my questioning. And Simon can't either. He pulled back to the safety of medical doctrine. He too hurt me. And now he has even taken up a career where he can retreat to the safety of orders, where to be different is just not permitted. So how can I ever expect him now to understand? He has gone further away than before. And that makes me afraid.

Brian is being great. However, he is the one who will be affected. He is the only reason I am hanging on. But he has had enough too. He no longer cares whether he continues or not. Life means nothing to him. There is no longer any purpose in his existence, just as there is no longer any purpose in mine.

Most of me no longer wants to keep fighting, keep struggling. What is the point? We are aliens, in a land with no spirit, starving intellectually and spiritually. We do not care about the good life, sport, enjoyment, money, etc. And there is nothing else here at all.

We are so isolated. There is a bit of me that wants to fight, to try to do something worthwhile. It is always the same. There is a total powerlessness.

And even in my death will be powerlessness. I do not choose this. If I had killed myself, I would have had some control over it. But this way - no! It is just a waste. I feel as if I have been killed by being here. My spirit is being eaten away, as much as is my cervix. It is quite symbolic. That has been of no use to me, although it is a most basic part of who I am

and my femaleness which is an essential part of me. And my spirit is dying.

I feel a sense of unreality. Then I feel grief. Then I feel fear. Then I feel desolation. I watched a tui bird cavorting in our trees which were lit by the setting sun and I felt the loss. It seems hard to think this could be my last spring. I felt it so strongly on Friday, and it doesn't abate much - just goes away when some of the other feelings become stronger. I had worked in the garden and then, when I rested later, I was aware of the pain again, low down in my left side.

I feel anger at the system which gives a false sense of security, telling me something which goes against what I feel inside. And my GP just makes noises saying that I have to trust the tests, when I didn't feel OK. But once you have been diagnosed with any psychiatric problem, especially mine, then they don't listen, they don't even try to comprehend what you are trying to say. He says that everyone has to come to terms with this. Yes, I agree. But almost everyone will just blindly do what the doctor or the specialist says. And not everyone has my history of questioning the clear smears because of what had happened in England.

But I don't trust them now. I can't trust them anymore. Will it make it worse? I am always against any interference. But I am scared. I don't know what to think or believe. Andrew said several different things which didn't tie up. My GP just goes on the defensive as though I am blaming him - which I am not. So what do I do? Instinct and what I get tells me not to go ahead.

But the GP's attitude doesn't help me. It is not so much the smear problem, as the underlying things. He just won't listen or try to understand that. He is only interested in going through the usual procedures, the treatments in vogue at present. Maybe they work. Maybe they don't. But I haven't been given enough evidence of either him or Andrew being right in the past. They are just there to make the patient feel comfortable - but they won't listen and really hear what I am saying - so they don't. Andrew is ordering me round and I don't feel I have enough information. But where can I go? I went to see my GP and he went cold when I talked of my feelings about this - the feeling that I would die.

He just says "I can't buy into that" to anything I am trying to say that is important to me but goes against what an ordinary, unthinking New Zealander would feel. He cannot cope with me thinking deeply about things. I should just do as he says and shut up. Damn it. It is my body and my mind and my spirit. He is not happy if I talk about my disillusionment and anguish here in New Zealand. He just doesn't feel that is OK. Yet that is what is at the root of my problems. And so my spirit is crushed yet again. There is nowhere to turn.

So, would it be better, really, if I did die? I would then no longer be a nuisance and an embarrassment to my GP. I make him uncomfortable if I try to explain.

Just as my parents can't understand - and don't want to. I just feel an embarrassment to them as I do not conform. I wish so much I could talk to Simon of these things. It used to clarify things for me as he reflected things back. But since he has gone, the

pain almost paralyses me. I am so afraid for him, so confused. I cannot explain it as it relates to things from way back which well up. Yet, I know he is enjoying his new job. But I can't force down the fear, both my own and for him.

I want to talk to him. I want him to know of these things. But I am afraid he would say I was manipulating so I cannot write to him. I am afraid he would say I am over-dramatising. I am not. I was really happy and doing well before this came up. However, it has brought to the surface a lot of things that were there anyway.

My physiotherapist said that maybe I am right about feeling I have run out of time. Maybe it is one last lesson I have to learn. That sort of serious discussion helped me far more than my GP's platitudes about everyone having to come to terms with this. That gave a purpose to it all. This is raising so many issues that I don't feel really ready for, so much confusion.

Yes, I want to talk to Simon, to see Simon. But it is complicated. He is a member of the medical profession and Brian has a dislike for most doctors, reckons they play God and so many are barely competent, as in all professions. He had respected Simon at first but unfortunately Brian's opinion went down because Simon refused take my unorthodox side seriously and because Simon let me down so often. Brian has no faith in doctors.

I hide my feelings from Brian and that is bad. I am trying to include him as much as I can but he is too closely involved. I feel caught between my own needs and those of Brian. This whole thing impinges

on his own faith and reason for living and struggling on too. And there is nobody else I can talk to. But I can't just talk to Brian about so much of it as he is too close to me.

It is real to die. Yet it is unreal. I know I must fight to remain well. But some deep part of me has given up. The destruction of a most essentially female part of me is the final straw. There is a sense of betrayal. I have worked so hard and done everything asked of me for 14 years. And this is the reward! I hurt! There is so much I want to do. Yet I am not able to do it. I have not the time or the energy. I have not the means nor the right. There is no point.

I don't find the world a very good place. In fact, there is not much I feel comfortable about in the world at all. People are cruel, deceitful, greedy, selfish, stupid, arrogant. Yes, there are some pleasant and helpful and unselfish ones but they are in a minority. Eventually, what is it that drives most people? I don't want to exist in all this. Yet, I love the natural world, love to feel the sun on me, to hear the birds. I had a lot to offer. It was rejected by all, again and again. I no longer want to go on trying. Yet that seems the coward's way out.

But I am not a coward. I have fought long and hard - and feel I have failed. So, I might as well bow out and leave the world to it. I don't know where I'll end up or what will happen to me. I have some theories but these have yet to be tested by me. It may be that this is the ultimate test. I don't know. I don't feel I'm handling it very well though. Better to do as the doctor says - This is the way we handle this problem. Get on with it as everyone has to and sign

here! But it is my body - and, more importantly, it is my spirit. And life at all costs is not everything.

I needed my feelings acknowledged for what they were – not judged or ridiculed. It is this aspect of not being acknowledged which seems to come up again and again in my diary. I hadn't realised how strong that need was – and still is. I needed support in my decisions and information so I could make the right choice for me.

Again, much soul-searching and anguish. There was so much confusion. In fact, all the other elements of my life were affecting me far more than the possible cancer. There was even an ambivalence about wanting to live at all. Life had become one dreary struggle anyway. Was this a way out? Yet there was that spark of defiance, of life, that would cause me to question and to fight.

Life is difficult for us and I am often depressed, although I have got better at pulling myself out of it. Sometimes it all seems too much and there seems no reward at all. Gradually I have come to be more at peace with myself. However, I am affected by Brian's feelings as we are so close and he finds life extremely frustrating. He has nobody of similar intellect or interests to talk to. His frustration often explodes. I am learning not to be affected by it but just to try to understand what is happening. But it is so difficult as we are so close.

Again and again in this journal, the themes of feeling rejected, and my fear of that, come to the fore. There is a sense of isolation and of not being accepted. I really feel I was born into the wrong time. I would have been much happier in Victorian times as an early settler. And coming back to New Zealand, with its narrow and insular attitudes, was perhaps the worst thing I have ever done. I am sure this has affected my health. It has certainly affected Brian's. I now feel as if I don't

belong anywhere at all. And over it all, I have this deep loneliness and a need to talk to someone who could possibly understand what I feel without judging me or rubbishing my feelings.

It was bad enough seeing my husband so sad and isolated here without those to whom I tried to express my feelings, such as my GP, ridiculing me for these feelings, telling me I shouldn't have them. Simon was the first person who had taken me seriously and had counselled me for three years before his untimely departure. Was it any wonder I felt at such a loss now? I needed to talk about death and dying, life and living, subjects which most people shy away from. But Simon didn't shy away and he had let me express myself freely. And I couldn't talk to Brian as he was going through too much himself.

I am sure one of the first thoughts to go through the mind of everyone diagnosed with cancer is "Help! I'm going to die!" This will then be mixed up with all the emotional and practical things of who and what are being left behind. I don't think anyone can fully comprehend death. I have watched countless animals of ours – cats, guinea pigs, birds, fish – in their last few hours of life and tried to comfort them. But dying is a very individual thing and must ultimately be gone through alone.

So how will my death be? Will there be pain? Will it be dignified? Will I be able to say goodbye without breaking down? Will I even be conscious? These are intrusive thoughts which rush in, uninvited, interspersed with the will to live and to fight.

The difficulty is admitting these thoughts at the same time as trying to be strong for those around. There is a desire not to worry those who are close and so these thoughts remain unspoken. This can hinder an understanding of life and of the richness of this particular phase of it. Maybe this is where a skilled counsellor could be of value. But most people do not have the benefit of this. I had been used to having Simon and

Marianne as counsellors and now, just when I really needed this service, it was no longer available.

I had asked to see, just one more time to clarify my thoughts, a counsellor I had been seeing at the local mental health clinic for my depression. My GP had requested this meeting but, for some reason this request was refused. This, too, affected me greatly. I am not a person who can stand alone. I think Brian is. He has had to be all this life. But I need people.

However, I didn't need this! Perhaps I would only live a little longer and die a horrible death. And I had somehow to cope with this on my own.

Indecision



I sat at my computer and tried to be rational and put down my worries and concerns about the purpose of all this. It just didn't make sense.

Tuesday, 15th August 2000

An agony of decision or indecision. Tomorrow I was scheduled to have the cone biopsy and it has been postponed because of my imminent period. As usual, I have had just spotting first thing in the morning, accompanied by low pain, and then nothing all day. It may be the same tomorrow or it may turn into my period proper. However, my temperature dropped by half a degree this morning so my period is due anyway. Andrew said that it is not a good time to do my surgery just before a period - so that ruled it out.

But, does that mean that I should not have it done at all, or just that I am not yet ready for it, have not yet come to terms with it? I just don't know, and going round and round, trying to reach a decision is killing me, and probably exacerbating any incipient cancer. I am so anxious and depressed, in tears. At

least it has given me a breathing space to try to work things out.

There are two aspects to my worries. One is the natural one of fear of what is going to happen, trying to come to terms with the loss of such a vital, deeply female part of my anatomy, one which has such a profound effect on the way I feel about myself. I am concerned that something may go wrong, that there is a cancer there that is further progressed than is obvious and that surgery will speed up the whole process. I am concerned at the disfigurement, even though it cannot be seen. I am concerned at my final loss of fertility, even though the chances of my conceiving are infinitesimal and I am far too old and weary to go through a pregnancy or raise a child now. I worry that I am doing the right thing, not making the situation even worse. Is it better to just try and improve the disarrayed cellular growth by life changes? I just don't know, but I feel instinctively that if I mess with a possible cancer, then it will fight back and make it harder for my body to change things.

And I am angry and confused and cannot trust because of the way it was not acknowledged here that I had CIN-II in England and I don't feel it was adequately checked out here. It was almost as if I was ridiculed because I chose to be in tune with my menstrual cycle and my body, keeping temperature and mucous records, etc. Yet I am acutely aware of my womb and all the subtle changes during the month. These are all I have to hang onto, to give me a sense of self. And I knew my body.

Those are all perfectly reasonable worries and

concerns and eventually I will have to come to terms with them, one way or another, and then I can make a rational decision about what treatment to accept. I know I have to do something, but whether an invasive procedure is the right course, I am not sure. I am certainly not denying what has happened. In fact, it is a fear I have felt inside myself for many years but nobody has taken me seriously. I had attended a colposcopy clinic but had been reassured that really there was no problem and that only a very tiny percentage of women ever had a worsening of my situation. The gynaecologist did a laser treatment but I had problems afterwards. He thought it would be fine just to watch it, that there is usually no problem. There was no indication that there was really any problem – it was just like having a wart burnt off a finger, I had thought. It was only later, when Brian managed to get hold of part of my medical notes when he went back to England, that I became aware they were trying to track me down for a follow-up. By now, it was too late. I was in New Zealand, unaware of the problem. However, when I finally got my notes, I immediately became concerned, realising that an abnormal smear is not just a minor thing that happens to most women, as I had been led to believe. It was then that I started having more regular smear tests and wondering why the results did not show up an abnormality as apparently had happened in England. Was there something inferior about the testing here? We had found a slapdash attitude in so many things here, so why not in this too. ‘She’ll be right’ is the NZ catchphrase. Only I wasn’t. – not in the way they mean, but I was in an absolute sense.

Perhaps it is just having a psychiatric history - I am disbelieved, thought a hypochondriac. But perhaps my feelings were right. Perhaps that means that I should accept this treatment. Perhaps the fear will never go away - but now I can't believe the tests or trust the doctors. So the fear will always be there, no matter what I do.

The other aspect of my difficulty in coming to terms with this problem is spiritual. I have always tried to be guided in all things by what seems to be what is required of me - not what I might want. I look objectively at signs in the real world, odd little coincidences of time and place, and try to work out what they mean. And the signs for going ahead with this procedure are not good. We have always got the message "You can believe in the doctors or you can believe in Me." (i.e. God). What has changed now that I have to make a perhaps life-threatening decision? It still comes down to the same thing. Perhaps I am not to accept any invasive treatment but to just put myself in God's hands and accept, meanwhile doing everything in my power to give my body the best chance of healing itself?

I know I have been and still am under tremendous stress and that stress will exacerbate the problem, prevent normal cell growth. Trouble is that I really don't know how to ease that stress in our present circumstances. The intellectually and spiritually sterile environment of New Zealand is killing Brian and, because of my love and caring for him and therefore sensitivity to his anguish, it is killing me. I cannot bear to see and feel his pain.

And this whole business just rubs salt in his

wounds. As a foreign professional who has high standards, he is ostracised by his NZ colleagues. All around, he sees incompetence and don't care attitudes which, to survive, he also is having to adopt, against everything he has believed in. He has tried to keep high standards, to be careful, to be honest, but been deprived of work for his pains. I was worried that my smear test results were all coming back negative and raised the question. I, too, had seen incompetence and lack of care and "she'll be right" all round me, and was not convinced that an English lab would find CIN-II while NZ labs came back with all clear. To me that didn't ring true.

Then the Gisborne smear test fiasco raised its head and I was even more worried. (The misreading of a large number of cervical smear tests in Gisborne and the subsequent disgrace of the lone pathologist who serviced the city. Many women were found to have advanced cervical cancer. But it is easy to find scapegoats afterwards. How much of the problem was the generic complacency?) I think that it is only after a policy change since Gisborne that my smears have given an accurate result. Also, maybe I should have had thin-prep and brush smears all the time. Still, that is hindsight - but it doesn't do much to make me feel any confidence. I do not blame anyone. It is just the NZ way - believe everything is wonderful and world-class if it comes from NZ and rubbish if it doesn't. Maybe this is unfair - but there is a strong element of this in the whole country and a refusal to even consider that there might be other, perhaps better, ways of doing things. The nation as a whole has a terrible inferiority complex.

And then there is the whole question of my purpose in life. When I was asked just before my first marriage finally fell apart what was my purpose in life, I answered that I felt each of my daughters balanced, one in each hand, like feeling the weight of a heavy ball and I was balancing their lives. But I also said that that was my task at that stage, but not for ever, and I didn't know what the future held. Shortly after that, my task in life changed to where I had little influence on my girls. I entered a new phase of life, became more guided and found myself trying to understand a welter of experiences and information.

I do feel I am guided and should follow what I am meant to do. I do have freedom of choice but it is up to me to determine the required course. I have been given much that is of importance to the world. I do not know how we can put this work out but I do know that it is important. What I do not understand is that my work is not yet done, so why have I been given so much and then perhaps am to be taken before it is complete? I have no energy and this is draining what little resources I can muster. I cannot devote my mind to what I must do, to being strong, because I am full of questions and doubts.

I was thinking that if I was a young mother, then my instincts would be to stick around as long as possible for my children. Then it would be a matter of life at all costs. However, they are now independent. Now my purpose in life as I see it is to help people see what is really happening in the world today, to put out the words that I have been given. I have not yet accomplished that, and I feel ever more weary. Am I

supposed to have time to do that, or am I supposed to go now, leaving the work unfinished - probably forever, as it is not acceptable to the right thinkers, and will never be disseminated? I just don't know.

I firmly believe that when my time comes, there is not much I should do to kick against it. Is this my time now? I just don't know. I have felt for so long that I have little time left. Now it seems as if that might be true. But I have not yet completed what I feel is my true life's purpose. Perhaps I have not even done much of it. So why should I be taken just yet? Unless it is fruitless - unless there is no point any more! If that is the case, then there is no point in my life any more anyway.

I need to be here to help Brian. We cannot even cope with two of us, let alone if there is just him. He would not stay in NZ, but maybe he, too, would die pretty quickly. He is not a particularly well man anyway and he has aged terribly in the past five years here in NZ. I try to help him. But I feel very constrained because if I say anything that remotely touches on things he is sensitive to, then he erupts. This then causes the most incredible emotional upheaval in me. And the repercussions are around in me for hours, if not days. But he has forgotten it within an hour. Maybe that's a male thing.

But I desperately need to be able to talk to him, to be able to be open and honest with him, to explore my feelings. But if I do that, then I tread on his vulnerability and he reacts. If I don't allow him to react, then he says I am just turning him into a New Zealander - don't care about anything. But his reaction causes me such pain and guilt. It is my

country (or was) and I feel such shame at people's response here. This is what is killing me - an eating away of my sense of belonging, sense of self, a betrayal of everything that made me as I am. And now my cervix, the centre of all that makes me female, is being eaten away. It feels like a betrayal of my womanhood. I can't explain it. But it is so strong.

I feel bad that I am not handling this as well as I should. I feel I should be able to just accept what I am told and get on with it. The trouble is, that is exactly what I have always done with authority - accept that THEY know best. And decisions have been taken on my behalf which have left long-standing psychological problems, which are still affecting me. The majority of these decisions affected my reproductive system in one way or another and so this decision is particularly devastating for me now. The worst of these were the decisions taken around the birth of my elder daughter. I never got over the callous treatment or the fact that I was not aware of her birth because of heavy and unnecessary drugs. And afterwards, when I had wanted to breastfeed, which was unfashionable in 1970, and had asked for assistance, I was told "Do you think animals are taught how?" And I had never even held a baby before! I was devastated. I became extremely depressed and ill and desperate for another baby, to experience what I felt I had missed. This did not do much for my first marriage or my bonding with my daughter.

I am left with the legacy of previous one-sided actions on the part of those who knew best and I never was able to come to terms with them -

especially as what I felt about what was happening was never acknowledged. They have led to my feelings of dislike for myself, my attacks on myself, my relationship/bonding difficulties with my elder daughter, my internal and illogical longings for another child and my deep feelings at my loss of fertility and womanhood because of my imminent menopause. I do not wish to add yet one more wound. Yet, if I allow cancer to spread, is this worse? I just don't know. I feel really overwhelmed by it all.

Thursday, 17th August 2000

The above was written after I had had a row with Brian. We were both just so on edge, stressing about the very real possibility of cancer and my death. This made us snappy and oversensitive. I am sure so many couples go through this at such a time. At least I was lucky in that my marriage survived it.

We had been about to set off for work. His job was in Tuakau and he dropped me off in Pukekohe on the way. But I had said something which touched on a sensitive area with him and he had felt I was criticising him. I was in floods of tears, scared, unable to decide, premenstrual, etc. The stress of indecision was really taking its toll. I just couldn't go to work in the end and so he went without me. I lay on the couch in the sun and went to sleep. Mary phoned and came round which was really nice. Then I came and typed up my feelings.

When Brian finally got home about 7.50 pm, somehow he thought the row was continuing where it left off. I took something as a criticism. He thought

I was ignoring him, etc, etc, etc. Stupid really. But he is stressed out over this thing too. He is trying to help me with my decision, trying not to influence me one way or the other, trying to be guided in all sorts of ways as to what is the best course of action. And it is extremely difficult for him. And my lack of decision doesn't help. I have tended to go round and round the subject. It also raises for him the spectre of being alone, completely alone.

It has raised very deep 'purpose of life' questions for us both. Brian doesn't really care much if he lives or dies - probably prefers the latter as he is sick to death of struggling fruitlessly. It raises the question of the purpose of the struggles we have had for the past 14 years, trying to do what is right, following the guidance we have been given. Would it have just been better to have been happy? Then probably Brian wouldn't be a man old before his time and I wouldn't have this hanging over me. But could we have lived like that with the pointlessness that seems to fill so many people's lives? I don't think so. It is right to speak out and struggle for what is right.

However, it does feel like a sort of betrayal by God. We have both tried so hard and now it all seems fruitless. And it was like a betrayal by the medical system too. I had done everything asked of me with regard to cervical testing, etc, even going so far as to get medical records from England to assist. Those records from England have been here in New Zealand for three years and never once been looked at. Nothing was picked up on the smears and I feel quite hurt and angry about that. It would not have reached this critical stage if anyone had looked

properly earlier. So, I would probably have had more options.

And I felt betrayed by my parents (though I have had a long talk with my mother today - probably the longest I have ever had. She explained her value system - which is to be happy at all costs as she feels it is all the time she has, one life, and so she should use it to be happy). I also explained mine (which is to live as good and decent a life as possible, using what skills I have to try and fulfil my destiny, whatever that may be, and to be guided to it by signs).

Being happy has little part in this. In fact, it is difficult to be happy while going against the flow. However, I do believe that this life is not all there is. This life is a test to see if I am worthy to pass on to the next life, which is not of this world. I was glad to have had this talk. But it was very clear that she felt that I am wrong and that Brian is to blame. She cannot see that it is ME as much as him. I have a different set of life values from her. I always have had and it seems to make her feel very uncomfortable.

Anyway, the upshot of Tuesday night and the continuing row was that I couldn't eat my meal, bolted out of the house, tripped and fell onto the kerb, belting my knee hard so I couldn't walk. I was just so distraught. The only thing keeping me going, making me want to fight this instead of surrendering to my first instinct of giving up, was that I needed to be here for Brian. And now he didn't want me! So what was there to keep going for? I sobbed myself to sleep, was woken by the phone and then talked to Brian before going back to bed. I was emotionally

destroyed. Mary had dowsed and made me up some Bach flowers for me and these did help.

Wednesday morning dawned. It was the day I should have had the cone biopsy. My period didn't come at all. In fact, there wasn't even any spotting! However, I had known that the decision would be made for me by my body. And at the critical time on the Tuesday, all indications were that my period would come (and it was due) and so the procedure was cancelled. Andrew didn't think it was a good time to do it at that stage of my cycle, in any case, so I was given a breathing space. In fact, I was sad in many ways. I just wanted it and the accompanying strain out of the way. Yet I was relieved too, as I hadn't quite decided. I had to come to terms with everything.

We went up to see Andrew on Wednesday at the time that had been scheduled for my biopsy. He was very good, explaining things, trying to get me to come round to the idea of having a cone biopsy done, or at least getting a second opinion. We both felt there was no point in that - and this was borne out when we went back and saw the other doctors I would have to consult for that. I wouldn't trust them at all!! They seemed orthodox right-thinkers, all in suits. No! Andrew did seem to understand my misgivings and worries, and he did understand my feeling of betrayal and acknowledged it, which gave me confidence. All the signs had been bad. I had changed my mind four times, back and forwards as to whether to allow surgical intervention or not.

My main worry is that this sort of intrusion would make something bad worse, or may not get it

all. Then I would be faced with more and more 'treatment'. The Hilaire Belloc poem *Jim Who Was Eaten by a Lion* from *Cautionary Tales for Young Children* always came into my mind whenever I thought of cancer treatment.

But could I really trust myself and be strong enough to go the alternative route? Brian reckons not and he is probably right. Do I have the stamina and the discipline required? But I do feel that cutting it out is not the full answer, yet it is logical. I had been going to talk to Andrew about trying to make life changes, etc. for a couple of months and then, if it was no better, I would have to resort to surgery. But somehow, I was just frozen and withdrawn in his rooms - back to that old state!

Anyway, after talking to Andrew, we went for a cup of coffee in the café at the back of Ascot overlooking 'the Crystal Palace'. We decided that it was better to just have the cone biopsy done and trust that he got it all and that it hadn't spread, so we went back to make an appointment for two weeks hence. The decision was made and I felt so much calmer. It had been a hectic day, with a visit to check up on my knee which was extremely painful where I had bruised and twisted it when I had fallen on Tuesday night. I had 10 minutes between getting back from that appointment to leaving for Ascot Hospital to see Andrew, so I was somewhat stressed. Now I was calmer and it was good.

That night I just ran myself a lovely hot bath full of Radox and soaked and snoozed. I felt much more relaxed and had an excellent night's sleep. I was just so desperately tired. I had had to go into work to do

the wages and was utterly wiped out by the time I got home at 8 pm. However, Brian had made the dinner which was wonderful.

The next morning, we were woken by a phone call from Mike a pharmacist from NHL who had been very helpful over Progesterone cream and then with literature, etc. to help me with CIN. I had phoned him when I first suspected that something was wrong. He hadn't heard from me as I had been unable to phone him back. However, he had taken the trouble to call and give me help over the oestrogen. He feels I could be over-sensitive to oestrogen and that it could well have caused the increased CIN. My last period seemed to confirm this. He is sending some literature and tapes for us to consider. He feels it can be reversed by hormonal use. My feeling is that I would like to try, at least.

I know there is a risk that it is a sudden, fast-growing cancer and that this is what my GP is worried about. However, my feeling and that of Andrew is that it is probably a continuation, a natural progression from the problems of seven years ago which I had understood at the time to be just routine, and that it is a fairly slow-growing cancer, maybe exacerbated by the oestrogen. So, if I can remove those effects, do everything possible to promote healthy cell growth, then perhaps normal growth will ensue and healthy tissue will grow and the old, damaged tissue will be discarded gradually. I would like a positive try at that anyway.

So, back to the beginning again. Only this time I don't feel desperate about it. I am not entirely happy about quack cancer cures. There may well be

something in many of them but I do not trust myself either. I would not have enough strength of purpose to continue. However, I do have confidence in Mike. He is professionally trained and has a strong interest in this field. This satisfies the scientist in Brian too. He has a profound dislike of the grubby pseudo-spiritual brigade. It would put me back in control of the situation, of my body. It would be up to me to do what I could to provide the optimum situation for its healing.

If this does not work, and I would like to go back for another colposcopy in 4-6 weeks to check for any changes, then I would go ahead with the cone biopsy. But at least I would have tried and it would teach me something. If it is a serious cancer, the delay may be a problem but, weighing all things up, that is a risk I am prepared to take. However, what I am proposing could only help my body prepare for surgery, could only improve my general health and that of my cellular and immune systems. This must be beneficial. If it is not invasive, then maybe I can bring about the necessary changes.

Maybe I have to use a combination of the two approaches - both surgical and hormonal. I just don't know. However, I feel calm about both now. Whatever choice I make now, is made with a fuller understanding of my cervix and its structure and function, the cellular growth process, the causes of the disordered growth, the possible treatments and their probable outcomes, the risks, and also my own feelings about my body and what is happening to it. I feel far more in control than I did when I was just being rushed through the system with undignified

haste. I can adjust much better now to whatever needs to be done.

And the will to live, the will to fight it, to learn from it has come through. I feel much stronger, much more positive than I have in the past week. I felt ashamed that I had broken down once or twice. However, considering how I would have reacted to something of this magnitude 2-3 years ago, I feel that I have handled it pretty well OK.

I know I need to make changes in my life - and in Brian's - to protect us both. We need more happiness and laughter. We need to lighten our lives. I don't know how. We also need acknowledgement of our work - but that will probably never come. We need to improve our general lifestyle, with more regularity, more rest, more exercise and better food. We have a generally good diet compared to many, but there is room for improvement. It will be good for us both to make these changes. The whole thing has brought us closer together, though when we had that row, it seemed as if there was no point in going on as it then seemed to have driven us apart with the strain.

I am just so fortunate that Brian is going out of his way to be understanding and supportive. It has actually strengthened our relationship and our love. I am able to talk to Brian more easily. I have opened up. I have talked about deep feelings that I know he thinks are ridiculous, like losing my fertility and the desire for another baby, which is entirely irrational at my age. He has come with me to all the doctor's appointments and listened in to all phone calls so that I can get his input as to whether something is straight or a good idea. He thinks more clearly than

me and sees straight through to the heart of things. Also he 'gets' what to do, is somehow guided, and I find this reassuring.

Some of the desperation has been caused by conflicting messages but I feel those were to make me look carefully at all the options and not just accept what the experts or those in authority, those in control say. Accepting authority is what I had always done in the past. This means that I can grow emotionally. At the same time as I break away from my fears of authority, maybe I can get back control of my own life and my own body and my own mind.

Having Brian come to appointments has meant that I have had to talk to a third party with him there, something I find quite inhibiting. However, I asked him to come, to include him as well as to help me by being an objective pair of ears. And that is a good thing. It has made me be open in front of him, even asking questions of doctors which I find difficult or embarrassing or which sometimes make me feel guilty. So, I have learnt a lot from this whole thing. Hopefully it was there for the lesson and will now be quiescent.

I now feel calm and ready to face whatever comes. It is not pleasant and it raises deep emotions in me to be examined in that intimate way, deep fears. However, it is something I must work through and come to terms with. Everything is for a purpose. Maybe I do have to let go of my cervix and all the baggage that comes with it. Maybe I do not have to lose the cervix - maybe just all the associated and hindering emotions that go with it. So many lessons, it seems!!

Pluses and Minuses



I decided to list positive and negative things about my situation to try and work out how I felt. The most helpful things were an acknowledgement of what was happening to me. Then later, after going through all the negative stuff, I realised how probably having cancer was actually helping me. I became very positive about how I could turn the situation round.

Things I have been told which have been helpful

1. When I commented to my physiotherapist that I looked out the window and felt it was my last spring and felt a tremendous sadness, she said perhaps you are right. Perhaps this is one last lesson, one last thing you have to go through and now you need to sort out how you are going to spend this last time.@ Maybe not a comforting thing, but its acknowledgement of what I had said was what counted. There was no denial, just an acceptance that I might be right.

2. The Family Planning gynaecologist said

that it was necessary for me to come to terms with my loss before I went ahead with a physical intervention. She, too, acknowledged my feelings of loss over a deeply female part of my body and the final loss of my fertility.

3. The chiropractor said that maybe I have to let go of that (and also of all the associated hangups). I need to think of it as a part of myself I no longer need, something that I can let go in the greater interests of the whole.

4. Andrew acknowledged that CIN-III might have been missed by colposcopy and it almost certainly was by at least 8 smear tests. This acknowledgement was helpful to me. I don't want to be angry or blame, but I do feel let down. He acknowledged it. No one is perfect and I know that. I just can't stand it when they intimate that they are right, while results show that they certainly are not.

5. The comment made by the nurse at Counties Care A&E clinic that I am now more in control of the situation, if I can at least try non-invasive methods first. Having the choice is important to me.

6. The reinforcing by the pharmacist of my instinctive feel about oestrogen use - that it

could have caused the sudden jump in seriousness of my symptoms. That had been rubbished by everyone else, all the 'experts', yet it was the one factor that had suddenly changed. I have always been against oestrogen use, instinctively feeling that it was dangerous for me. (I had had a difficult and dangerous pregnancy with Miranda after several early miscarriages. The only way I held onto this pregnancy was total rest and progesterone injections. It seems I still did not make sufficient progesterone to counteract the oestrogen output and I had felt it helpful when I had used progesterone cream. Oestrogen seemed wrong.) Also, he feels that I may be able to reverse these changes in the same way, over time.

7. My daughter's reaction "Oh, Mum!"

8. A spontaneous hug from friends has meant so much. I feel their support, whatever decision I reach. That means a lot. And I value their different approaches, based on their own experiences, training, fears and emotional attachments.

Unhelpful reactions and things that have been said

1. My first GP's reaction that I just have to come to terms with it - said only a couple of hours after my being told the bad news

by the gynaecologist, that he could see the aceto-white area and was unhappy about it.

2. My GP's reaction when Brian asked what had changed for the tests to be so wildly different over two weeks "It's just Jenny's cervix". That was a glib answer and also instilled deep fear that such a change could take place so quickly. It did nothing to cause Brian to accept that doctors are scientists!

3. My mother's reaction that "Oh, I have had bad smears all my life, dear. I haven't bothered to do anything about them. Why are you worried?"

Maybe some of these were said so I wouldn't worry but I needed honesty and to be able to confide in safety. I needed to understand what was happening.

Negative feelings

1. Anger and betrayal at the system, New Zealand, God and my body.

2. Guilt - That it is perhaps because of something I have caused myself, one way or another.

3. Fear - of the uncertainty, of the discomfort and feelings aroused by the procedure, of losses of fertility, femininity,

or sexual feeling, fear that it is more serious and that nothing can be done so that I will suffer a painful and undignified death.

4. The anguish of feeling abandoned and alone.

5. That I just want to die, to give up the fight, that there is no purpose left any more.

6. Indecision as to what to do for the best. And I could not find a clear answer in the signs either. I did not want to make the situation worse.

7. That it is a mutilation of my body, a disfigurement, an amputation of an important part.

8. That it is important to me to have another baby. (This was totally illogical as I was too old and tired to be able to manage a baby, let alone the ensuing toddler. And Brian had been through that stage of life 20 years before. It would not have been fair on a child either. However, after the traumatic experiences of the birth of my first baby, Nicki, in Scunthorpe, Lincolnshire in England and then the many miscarriages and then the difficult pregnancy with Miranda, I had still harboured a desire to experience it properly. When I remarried, this surfaced more strongly. But it was not

to be. But logic doesn't come into it in this area of a woman's mind and body as any woman who has struggled to conceive or bring a pregnancy to term will attest. The monthly disappointments start to eat away at you. In my case, I already had two daughters, but the crazy maternal urge was still strongly there.) I must let this go and look to a new stage of life.

Positive things to concentrate on

1. That there is a purpose in everything and to seek out the many ways this can help me to grow in understanding and acceptance.
2. That it has brought Brian and me closer together and forced me to open up my feelings to him about things I feel a bit foolish or embarrassed with. Communication has improved.
3. That it is an opportunity to make some changes in our lifestyle that will benefit us both.
4. That I must let go of all the old, frightening feelings relating to my sexuality instead of leaving them damaging my cervix. I must visualise them falling away.
5. That I must breathe in life, relish the sunshine, the birds, the touch of the breeze

on my skin. I must be thankful and find some joy in each day.

6. I will make more time for creative and pleasurable things in life. I must continue with my art and music, things which give me scope for self-expression.

7. I have been faced with a possibility of death and know I can face it. It has also made me more aware of how much Brian would lose if I went. I do not want to leave him alone.

8. Whatever happens, I must retain my faith and trust in God, that I will continue to be guided right up to the end and beyond. That keeps me going, and even when I doubt, it is not for long. I try to accept.

9. I have proved I am strong enough now to cope with a major decision and threat in my life. Although I have not done as well as I would have liked, in that I have fallen back a few times, I am overall pleased that I have coped fairly well and come through a stronger person.

10. I have not allowed myself to be bulldozed. I feel more in control of what happens now. It is my decision, made in conjunction with Brian and with my own philosophy of life.

11. I have learnt how to express my feelings in words and, on the whole, friends and medical personnel have listened and acknowledged, each to their own ability. So, I feel more value in myself as a person, able to do what I feel is right, making a considered decision about my own body and my own health while listening to and accepting advice.

12. I am glad of the experience, emotionally harrowing though it is. It has helped me to grow through one more stage and to understand about so many things. Everything has a purpose. Everything is for a good reason and can teach us what we need to know.

13. I will go onward, trying to clear up all the clutter, trying to have confidence that we will succeed, trying to make everything as good as possible, so that even if it is my time to go from this world, then I have at least left it easier for Brian. However, I must just trust that I will be here long enough to help him with our work.

This exercise clarified a lot for me. Just as a way of evaluating my life, it was good for me to do this, never mind worrying about possible cancer. I felt quite positive at the end of it all.

The Cone Biopsy



We arrived at Ascot Hospital on 30th August 1997 and that was when the problems really started. Brian had trouble parking so I left him outside and made my way in alone, in great trepidation.

Some five minutes later, he came in, after a disagreement with a Chinese woman over a parking place. We sat in an office and Andrew went through the procedure. I was in a bit of a daze. Brian made some notes. I would be given a local anaesthetic and he would carry out the laser cone biopsy and then I would be left for a while to recover. He said that this procedure was curative in most cases. Only a small percentage did not have clear margins left. "Huh," I thought, "Only a tiny percentage were not cured after ordinary laser treatment is what they told me in England, too." So was I to be in the small minority again?

Andrew indicated a changing room. There was only one gown amongst all those on offer that had a pattern – of sheep. I put this on, the usual elegant design with only back ties to protect my modesty. I danced out to Brian, making light of the situation, commenting about the sheep to the slaughter. Andrew indicated they were ready for me in the theatre. He invited Brian to come in too. It probably helps women to have the comfort of their husband.

I was strung up in the stirrups – most inelegant. Andrew

took up his position at the bottom end of the table and there was a nurse at the head of the bed. Another nurse knelt down near the foot of the bed, to help hold some instrument. Brian was holding my left hand and I clutched it. Brian watched what was going on. He noted with some surprise that Andrew didn't have any medical clothing on – no white coat. He was dressed just in his dark suit, ready to go back to his rooms for another consultation.

“Cough, please,” said Andrew. This pushes everything down so he can easily give the local anaesthetic. He waited a short while and moved the laser over, ready to begin. Brian could see nothing, given the screen. However, he did notice the smell of burning flesh, in spite of the ventilation system. Horrid!

He became aware of my gripping his hand tightly. The nurse seemed utterly oblivious. Brian shouted to Andrew and the nurse “She can feel that. You haven't given her enough anaesthetic.” They did something and after a few minutes it resumed. I was turning away and sobbing quietly, sickened by the smell of burning flesh. It all seemed wrong.

After perhaps a quarter of an hour, it was over. Andrew showed Brian the small lump of fleshy tissue in some transparent liquid in a sample jar. Now it was up to the labs to tell us the worst. Unfortunately, as I was distressed, Brian didn't think to photograph it as he normally does with everything. This made it difficult for me later, when trying to correlate it with what the laboratory found. In fact, he had hardly been able to make notes in his notebook as I had gripped his hand so hard.

Andrew reeled off a list of Do's and Don'ts – “No sex, no baths, no swimming, etc, etc.” Then they wheeled me into the recovery suite. Brian sat with me for a while, but all I wanted to do was sleep. So he went off to sort out a laser printer.

It must have been an hour and a half later when Brian got back and I was still woozy as the experience had been

overwhelming and I had 'withdrawn'. I just knew it was cancer – somehow I just knew, and had said so to the nurses.

Brian brought the car round to the front of the hospital and took me home. I just wanted to sleep. Whether it was the medication or the enormity of it all, I didn't know.

By the next day, I felt a bit better, though very anxious. I went out into the sunshine and sat doing a pastel sketch of the garden. My friend, Mary, came round for a chat which was nice for me. However, after another day or so, I started to feel distinctly uncomfortable and unwell. I couldn't work out what was wrong. I was feverish and itchy. Maybe I had an infection. A visit to the local A&E clinic confirmed this. Andrew had left a medical tampon because apparently I had bled far too much. But nobody had told me or that it had to be removed that night! Brian also heard no instructions or even mention of this. Yet another medical misadventure!

It was an anxious wait until the results of the cone biopsy came back. The theory is that it burns out a neat cone of tissue which can then be checked by the laboratory. If it is big enough, it also cuts out all the malignant tissue, if there is any. That was what Andrew had hoped for. But it didn't quite work out that way though.

The Diagnosis



6 September was the diagnosis date, that date which is as fixed in my mind as the due date of a baby.

Andrew suggested a second opinion as I was so unhappy. I asked for a copy of my notes and was appalled to find how scrappy they were and that they were not written up until anything up to 14 days after a visit. Everything seemed unsatisfactory and confused.

Yes, I had already been told about the smear that it looked like invasive cancer so I was forewarned in part. However, to hear those final words was almost too much and I reacted with shock and tears - and then anger, a real anger that my concerns had not been heeded earlier, before it was too late. In fact, my fears and worries had been denied, almost ridiculed. "We have the best laboratory facilities in the world," had been my GP's response. Now I see it, with such deep anger, for the arrogance it was.

Worse was to come. "It is a poorly-differentiated cancer," said Andrew, "which means that it is most likely fast growing and less responsive to treatment. You have two choices and each has been shown to have much the same survival rate. You can either have radiotherapy or a radical hysterectomy."

I couldn't really take it in. Thank heavens Brian was with me, cool and scientific as usual, making notes in his notebook

and asking pertinent questions. His first thought was that perhaps internal radiation would be appropriate, given the symbol for Radium is Ra, the name by which we refer to God. However, apparently they use caesium, so that didn't seem to fit. So I enquired about a hysterectomy. I dreaded this as I still had secret but ridiculous hopes for another baby, irrational though that might be. However, if it would eradicate this cancer, then perhaps I would have to go through with it. I tentatively asked about the tumour. It is a tumour, isn't it? Andrew said that that was the correct way to see it. Yes it was a tumour – a scary word.

But, no! It was not a simple hysterectomy that he proposed. It was a radical hysterectomy, a Wertheim's hysterectomy. This word radical hit me like a sledgehammer and I queried it. Yes, it was indeed radical - as well as the uterus, they would take all the pelvic lymph nodes and the top third of the vagina! This was too horrific to contemplate. Surely I needed those nodes for my immune system?

Then came the soothing words. Of course, I had a 90% chance of survival if I had either radical surgery or radical radiotherapy. But then it was explained that this was only a 5 year survival! Why not longer? Because records didn't go that far! That seemed strange. Cervical cancer has been around for a lot longer than 5 years. Was this because most didn't survive much longer than 5 years anyway? I was starting to smell a rat. Up to now in this tragic process, I had always been in the smaller, unlucky percentage. Why should it change now?

I railed and sobbed. The poor doctor. But I was angry - angry at a system that could have allowed led to this. The 'world class laboratories' had supposedly read five clear smears. And I was angry that he and my GP had not listened to my concerns, had not taken seriously the English notes we had managed to get hold of. These showed that the smears were not clear in

England so why had they been clear here? And could the pathology be wrong? It seemed very convenient to me that the smear, a quicker procedure, was reported after the biopsy, as if they were corroborating each other, rather than being independent. And how could a smear show invasive cancer? That can only be shown by biopsy, as I understood it. Brian had much contact with laboratories in his job as a waste water scientist. Just recently, he had had several examples of mixed-up samples and wrong results. Was this just denial? Was it just desperately clutching at straws?

But there it was. I had cancer - and probably a fast-growing variety. And I had some pretty hard choices to make. To make it worse, it involved the most intimate and sensitive part of my femaleness. I had always joked with my girls that I would >die with all my bits=, mainly thinking of breast cancer. Now I had to decide in all seriousness about this. Nobody can tell how they will react it happens for them.

It was a sombre trip home. Somehow I was numbed. And it must have been even worse for Brian, as he was the one who now had to contemplate being alone. I think people often forget the husbands or wives, the family, the friends.

A Heartfelt Plea



I had had the cone biopsy, on 30th August. I hadn't been at all keen, feeling it might make things worse. I had now, on 6th September, just had the news confirmed of my cancer. At first I was numb and didn't react at all, except with anger and tears at the gynaecologist's office. Then I became very quiet. I needed to think it all out. I went to bed as usual, but somehow sleep eluded me. Brian was sleeping gently and I didn't want to disturb him so I got up quietly and went into the sitting room, picked up pen and paper and began to write by the light of the lit Christmas tree.

Yes, that sounds strange but we had celebrated a mid-winter Christmas with friends as it feels right to us at this time of the year. Although I am a New Zealander, Christmas on the beach is not how I see Christmas now. I suppose that's the result of a couple of decades in Europe. With all the worry over the cancer, the tree had never got taken down. The lights were very comforting to me now.

I thought back to the month before my first European Christmas, when I was in Vienna. The shop windows were exquisite, with animated displays, candies, lights.... It was the era of the maxi and midi skirts and so all the women gave the impression of being part of a Viennese Waltz. My husband and I then hitch-hiked on round the Mediterranean and we spent

Christmas Day itself in Annaba, Algeria, where we eventually went to work and live four years later. The Arab hospitality was so warm. My second English Christmas was a white one, with a hoar frost so that all the trees were sparkling. We were staying with an Austrian friend and so we had all the trimmings, with real candles on the tree, and a proper Christmas Eve. It was magical.

Those were warm memories of the past. Now I was wondering about the future.

2.15 am - Thursday, 7th September 2000 - Night Thoughts

I got up and found myself aimlessly wandering in circles round the house. Sat down in an armchair and sobbed and sobbed. It is a beautiful night and as I calmed down, I could see the silhouettes of all the deciduous trees in the front garden set against the light of the cloudy sky. Soft rain started to fall and matched my tears. It has got heavier but still a gently, peaceful sound. I can hear it pinging on the metal chimney of the wood-burning stove beside me.

I had tried to sleep but found myself moving away, out of my body, whenever I closed my eyes - almost practising dying. But I'm not ready yet. I remember the night when I wandered round like this and decided to kill myself, to walk out into the night. That was 22nd February last year. I thought of just walking out into the rain and being part of it but decided that was crazy. So instead, now I am attempting to put down my thoughts as I'm feeling them.

What is the purpose of this ordeal? In part, it is probably self-inflicted from hating and attacking myself and there is a terrible sense of guilt from that. And self-reproach that I didn't have the strength of will to overcome my pain and stress. It was wrong and now I have to take the consequences. But why should Brian too?

I had thought perhaps it was just to make me change my way of living, just a warning, and that it might work out OK after that lesson. But this is far worse than I had thought. Every test gets worse than the one before it. Is this disease just galloping at speed through my body? That frightens me as I have no control and no time to try different measures. I am reminded of my cousin, Bill who had recently died of cancer.

The worst thing is not so much the cancer but the not knowing if it has been there for the past seven years and has been slowly changing. If I had known, I could have tried alternative treatments to do something about it. Or perhaps it has been dormant and has now been triggered by something I've done or that has happened to me? Or is it is something totally new and voracious? Each of those scenarios I would handle differently. But I just can't trust the testing process. And today just proved it. Why do they always cover themselves instead of being honest with patients?

If you can't trust the testing and are unsure of the doctors, what can you trust? I douse with a pendulum to determine what supplements, etc. are good for me at a certain time. My pendulum still seems to give an accurate account, though it doesn't

call it invasive at the moment - but says it will become that way if left. Ra has been accurate too, though it is easy to read things more favourably. I have to trust these two things (though it is not correct to call Ra a 'thing'). The ancient Egyptian name for God which we use as it doesn't have the powerful overtones of 'Jesus' as being God which seems to permeate Christian society. To us, God is the all powerful Creator, not a sacrifice for sin. I prayed for guidance.

I then continued with this early hour's musing, as if talking to Simon. For several years, I had always been used to being able to talk to him about things that bothered me emotionally and it was desperately hard going through this without that support. I find talking or writing letters is the most therapeutic thing for me. It personalises it and makes me feel the emotion rather than being detached. I suppose it helps the reality.

Brian was sound asleep in bed. I didn't want to wake him which is one reason I had got up - so that he wouldn't wake with my gentle sobbing. He was having to face losing me and I didn't want to stress him any further than necessary. So I turned all my pain and feelings as though talking to Simon as I had been able to before he went. I so needed to have someone independent, yet someone who knew me and what makes me tick, someone to talk to as a sort of counsellor while I sorted out my feelings.

I want to write, yet I don't. You haven't responded to my needs, to my pleas, and the hurt is too great. So I pull into myself and try to wrap something round the pain in my chest that never goes away if I think of you - or even when I don't - but the hurt is still

there. I don't want to think of you as it just causes me pain. I want to care about you. You see, I am interested, as a friend and someone who cares, in your life and your happiness and well-being.

But then, all my warm thoughts bursting out of me get crushed by the pain of feeling you just don't care. You don't care enough as a friend to have wished me well before what to me was one of the most major decisions in my life. To you, it may seem just chopping out a bit of redundant tissue. But you knew how I felt - or I'd tried to explain it. I waited - but nothing! In the weekend, someone even did a U-turn in a Landcruiser outside our house and there was that familiar grating sound. My spirit leapt, even though I knew it was in vain.

I'm fighting for my life, to survive long enough to help Brian do what we feel we must. I really feel I'm facing death. The results were much worse than they thought - invasive cancer. So it's gone from clear last year to CIN-I to CIN-III two weeks later, to CIS in a biopsy 10 days later, to invasive cancer, Stage 1B, three weeks after that. Either it is galloping or they got it completely wrong for years. Neither possibility would surprise me. The not knowing what is for me the worst thing about it.

Strange, a really nice picture of my mother just fell out of this pad (2.45 am). She finally got round to phoning last night. Dad obviously hadn't told her that I was having the cone biopsy last Wednesday. She wanted to know if I had cancer or not. I haven't told them the results I got today as I have just withdrawn into myself and can't talk really. I do wish there was someone I could really talk to though.

The worst thing is feeling there is no one now. And feeling the pain, not only of losing you being there but your lack of communication, even on something as major as this. And the worst thing is that I have to bear this entirely alone as I can't give Brian any idea that I am so hurt by you. That would make him angry and I don't want that. He kept getting that it was not a good thing, that it was unwise, when I was seeing you but that it was my choice. I could just go my own way - which I did. I felt it was right in some ways, but I did have misgivings at times. Still, I held my ground as I did feel I was making progress on my emotional problems. But now I cannot let him know and so I suffer alone - and you don't respond.

I'm sorry. This sounds really accusatory towards you. It's not meant to. But you said "First do no harm". But the lack of communication is doing harm. I'm trying to feel good about myself, to keep living, to see a purpose. And I need to know there are some friends, some people close to me. And I had counted you among those very few. And you claimed to be a friend. But I'm not sure. When I see you, I'm sure. And that hurts more than you can ever know. I need to know you are there. That helps me get well. This way I feel pulled back all the time. It's like something tearing at me. I try to let it go, but it's always there - day and night.

When I get a brief note, I feel flooded with warmth - and that's healing. Otherwise, I'm tense and anxious. Maybe that's stupid. I'm not dependent on you like before. I am coping OK and Brian is being really good, although I fear for his health as well -

he's not well, with no energy, memory going, lethargic, dispirited, just crawling through the days.

But I do need to know you care enough to write. You have been a very important element in my life for a long time. I can't let that go easily. And I wonder how much of this now is because of the loss. They say cancer often strikes within six months to a year of a strong emotional loss. That's not blaming you. It's just a fact - and I'm the one who didn't cope. But you made it a lot harder than it needed to be because you are bad at keeping in touch.

I know I am too, with some people. I suppose most people really are. The intention is there but I don't get round to it. And I do appreciate everything you've given me. I learnt such a lot - and continue to do so. And it was good to be filled up with warmth by your caring enough to help me when life seemed so empty.

But now I'm facing death. I try to work out the purpose behind it all. I try not to blame myself - but I can't help it. I try to be strong as I know it's the only way to survive and I must survive for Brian or he would be totally alone.

I look at things, touch things, smell things, hear things and feel the poignancy of the moment. I may not experience them much longer. In some ways, there isn't a full realisation yet. Feelings are sort of cushioned, yet my senses seem more alive to inputs. The clouds were so beautiful today - like a Constable painting - and I found myself saying to Brian on the way in to get the results from Andrew, will I be as a cloud?

Maybe I will survive a bit longer. I don't know.

I'm not afraid of dying but I resent the loss of my strength and the cutting short of my time. And I fear the pain. I must try and fight, though. I don't know yet what course of action I'll take - probably radio-therapy. I have an appointment on Monday to discuss options. The consultant apparently specialises in gynae cancers. I'm sick of it already - and it's barely started. And I really don't want to lose my job. I was just starting to enjoy that, despite the difficulties. It was somewhere I could be me and I got on well with the other staff.

I don't want surgery. I really don't think I'd survive a hysterectomy. It was bad enough with the cone biopsy. I've been feverish since. Andrew had left a large tampon in place and the nurse didn't say - or if she did, she didn't make sure I'd registered - or Brian. The only thing I registered was Andrew's oft-repeated admonishment "No sex, no internal tampons for a month." I had no idea it was there for almost 48 hours and got feverish and aching. OK then for a couple of days but the fever's been back for 3 days and nobody knows what it is or why. So that again puts me right off further surgery.

We'll see. I'm getting tired now so may as well try and sleep. It's 3.30 and I must rest. It's all too much to take in and my emotions have been so strung out for 5 weeks now.

It seems as if I was still too dependent on this doctor and I admit that I was. But I needed to work through things. I did not want to stress Brian any more as I could tell the whole thing of the cancer and his probable loss of me caused him deep distress. I knew he would be hurt if I spoke to Simon but

somehow I needed someone outside the situation but someone who knew me well. I would say Simon knew me and what made me tick better than anyone else. And he had claimed to be a friend. But was he really? Or was that something I had wanted to think. After all, I had been seeing him regularly for counselling for about three years. He also knew of my vulnerability and my crazy desire for another child. So, to me, this cancer was hard on many levels, not just the physical one. And I desperately needed friends to talk to - and Simon was a friend as well as a doctor, or so I thought. It was an impossible situation, really.

A couple of days later, I sent Simon an email letting him know the results of the biopsy. My feelings about the cone biopsy had been vindicated. I had not weathered it at all well. Perhaps I shouldn't have had it done. The only thing was, it now told me the worst, so that I knew what I was fighting.

Simon,

I thought I'd let you know. I have now been diagnosed (last Wednesday) with invasive cancer. The official diagnosis "Poorly-differentiated Invasive Squamous Carcinoma" which is apparently the faster growing variety. Andrew did not get all the tumour - it goes further up the canal. The bit they measured was 5mm deep by 1cm wide, so is classed as Stage 1B. Great news! I had prepared myself for micro-invasion, but not for this - yet I think I have known inside for quite a long time.

I don't know what my next course of action is to be. I am being pushed into a hysterectomy - supposed to see the consultant soon - but don't feel that is right as I wouldn't survive it. I have been right

in my feelings all along and the medics have all been wrong. I have just parted company with my GP over this subject. He will not support me at all if I choose anything other than what he wants so I asked him "Am I on my own then?" No answer! So that's that.

However, I had only just walked in the door from that appointment when I was phoned by someone to put me in touch with a homotoxicologist who may well be the answer. I must say I am not thrilled with the prospect of any of the treatments and I am very, very angry at the way things have been handled in such a sloppy way since I came here. I have been trying to press for several years as I was worried. And it was not picked up in 6 smears and 3 colposcopies! So the odds are not good for a cure either. I cannot trust them.

The cone biopsy had complications. I knew in advance it would. Andrew didn't use enough anaesthetic so poor Brian's hand was almost broken as I squeezed it so hard. He had to tell the nurses as they didn't seem aware. Then apparently I bled badly so he inserted a large swab at the end of the operation which was supposed to have been taken out that evening. I didn't even know it was there and so became feverish, faint, aching and in discomfort by the time it was discovered and removed 48 hours later. It seems the nurse was supposed to tell me it was there and advise on it. And I have also been very feverish all this week, but they can't find anything - probably stress. So, if that can all go wrong in such a simple thing, what chance have I in something major? I feel that there are other areas of cancer in me and my immune system is pretty shot so there is

little point in operating to take everything away and leave me with a lousy quality of life. I would honestly rather be dead. It is not life at all cost.

I have a huge fight ahead of me. I hope I am up to it. I held back from telling you because you hadn't been in touch and I withdrew into myself. I feel really angry and let down by the system and I feel guilty at myself as I am bothered I might have caused or aggravated it in some way. However, I have picked myself up within 24 hours and sought out what avenues of help and support I can find, seeking for information so that I can make a really informed decision - and one that I am relatively happy with and can accept, given the circumstances. I just wish I had a doctor I could trust.

It is tough on Brian as he, too, is far from well. I suspect he has some similar problem. It serves no purpose, he says, to find out. But it draws us closer together, except in those moments when the terrible strain starts to tell. I would rather have a couple of reasonable years now, to complete what I must do and then go, rather than something radical now which I see has having little chance of success, given the past track record. That would mean my life was destroyed now.

Sorry - not cheery news! Hope yours is better. It cheers me immensely to get a note. I need to keep strong and not go up and down as now. And I guess I'm scared of what is involved in the treatments. Just when everything had started to go right too!

Jenny

Back came a really thought-provoking hand-written letter:

Dear Jenny and Brian,

Sorry to hear the news. Have you decided what you are going to do Jenny? Think carefully about what you wish to do - your body is the vehicle for your soul - it is not what makes you who you are. If you decide not to proceed with the surgery, that is a valid option if it's made for the right decisions. If the psychological distress that it may cause is the reason, for example, then that is valid. If fear of adverse outcomes is the reason, then that is not so valid (because it is reactionary to your fear of the system.)

A hysterectomy is more invasive than menopause but the outcome is the same - it is the end of the reproductive period of life. You must look to your life and assess what you still have to do - do you still have work to do? That will, I think, lead you to the answer.

Menopause (whether surgical or hormonal) is a time of change. It makes you no less a woman. It is a part of the progression of womanhood.

Good luck, Jenny - I hope you have some closer help in arriving at your answer.

Simon

I needed that acknowledgement, even though I knew there was nothing anybody could do. It is the hardest thing when you are diagnosed with cancer. People seem to drift away as if they are scared of it. Perhaps it arouses their own fears. But just when you need friends most, they are not there. It was so important

to me that Simon had written and not pushed me into any course of action but given me something to think about - just like our old discussions where he had tried to help me think around areas that bothered me. I just had to get strong enough to handle this on my own. As I had said in my email to him, *I have a huge fight ahead of me. I hope I am up to it.*

Trying to Find the Right Way



As soon as I got the news of my diagnosis, I immediately tried to find out more about this sort of cancer. I needed all the information I could get to help me make a decision on the best way forward. This was easier said than done.

Of course, I struggled with the internet and came across some interesting statistics.... One of the things that had the most profound effect on me was a piece about how women, who had been diagnosed during pregnancy and had a radical operation at that stage, taking away cancer and baby and all further chances of children, all died. However, those whose pregnancy was allowed to continue and who had surgery immediately after giving birth all survived. They had a lot to live for, whereas the other group had nothing left.

There were other scary things I found about life expectancy and the general progress of the disease. It struck me that not much was really known about what would happen if the disease were treated in a non-invasive way, by trying to build up the body and give it the strength to fight off the cancer.

There had been the ill-starred 'Unfortunate Experiment' at National Women's Hospital some years before where an attempt was made at determining the natural progress of this

cancer if left alone. I could understand the reasoning behind it as the standard treatment for cervical cancer is very radical and destructive. All hope of further motherhood is lost and the side effects can be brutal. The only problem with the National Women's experiment was that the women concerned were not informed of this and were not given a chance to generally improve their health and guided as to what were the right nutrients which could help. Perhaps not much was known about this anyway.

Sandra Coney had been involved in an exposé called *The Unfortunate Experiment* and was angry about it. I phoned her to see if she could be of any help to me. She was onto her next cause by now and was no help at all.

I also telephoned the lawyer for Colleen Poutsma, up north who had been in the news all during this period. She was dying of cervical cancer which had not been diagnosed until it was too late. She had only been checked by ultrasound, which apparently is very poor at showing up cervical cancer. I wrote to Colleen but never got an acknowledgement from anyone. Anyway, her lawyer was adamant I should go in for surgery the very next day. She reckoned she could find someone who could do the operation. I was not at all happy with this rushed approach. I had phoned to see if there was any point in following up my concern that five smears had been missed, not to get medical advice.

I went to the local Family Planning to discuss my situation. At least the doctor there answered me thoughtfully and said that the situation was not desperate and that I had some weeks to come to terms with a hysterectomy. She said that women who do not have this adjustment period often suffer badly from post-operative depression when their body realises what has happened. I knew this was a very grave danger with me.

I heard of who were doing cancer research

in Dunedin and telephoned them. All I got was “Send us all your details”. I didn’t have the energy to put it all together, and obviously they were not that interested.

I telephoned the Ministry of Health. I received a phone call back on a mobile. When the mobile cut out, there was no follow-up call. I was just left hanging and nobody ever came back to me.

I had asked about getting my smears reread in Sydney. I had spoken to someone helpful in the laboratory who referred me on to the Henley(?) lab in Sydney. They were quite willing to reread my slides for me if I could get them to them. There was a total unwillingness to release my smears. I was told that all smears were going to be reread in the near future and mine would be with those. When I commented that I needed the information NOW to make a decision, I got no response other than “It doesn’t really matter. It will all be taken away, anyway.” That was not what I had decided at all. I was trying to work out whether this was a continuation of the previous problem, which I could perhaps allow to run for a bit longer while I tried to turn the situation around, or whether it was a very fast-growing type of cancer which needed urgent and aggressive treatment.

All this was most unsatisfactory. There seemed nowhere I could turn. Everybody had their own agenda and it was almost impossible to get any real objective advice.

I had an appointment with my GP to discuss what to do next. I had left a message on Mike’s phone at Pharmaceutical Compounding, hoping he might be able to point me in the right direction. My GP just wouldn’t consider anything but the orthodox route. My last words to him were “So, I’m on my own then.” There was no response.

Back home, feeling pretty depressed and alone, I saw that there was no message on my answerphone. So even that had drawn blank. However, I hadn’t been home five minutes when

the phone rang. It was Mike's secretary and she told me that they had just taken on a new person from South Africa who was skilled in the dietary management of cancer, a homotoxicologist.

Serendipity



A fortuitous event had occurred indeed. When one door had closed with my GP, another had opened, within an hour, with the homotoxicologist. He prescribed a desperately strict diet consisting mainly of rice and vegetables for a few days, progressing to something quite edible after a bit. He warned me that if I broke the diet, I needn't bother to come back. There was no meat, no dairy, no wheat, along with many other foods which were basic to my diet. I was also receiving help from the pharmaceutical compounding company who had put me in touch with this help. This gave me the confidence to not rush into any orthodox treatment.

Mike had already been really helpful about indole-3-carbinole which is one of the active ingredients in cabbage and he had sent tapes of various papers and lectures on the subject. They had sent me literature about indole-3-carbinole and how it can help early stage CIN problems. He also sent a video of a conference on this subject. I had already started on indole-3-carbinol, as well as a good lashing of antioxidants, etc. even before the cone biopsy. So, when I had found out it was cancer, I had phoned to speak to him to see if he had any ideas on how I could best fight it. I had to leave a message on the answerphone and there was no return message when I got home. I felt I had nowhere to turn. But within minutes of my arrival home, now

here was this message! They had only just taken on someone, recently arrived from South Africa, who could most probably help me. He was doing work on diet and cancer. What timing!

I was really not happy with the normal cancer treatments, feeling strongly that they would compromise my immune system, if not destroy it altogether. Now I had something positive to work with and some professional guidance. I had already put myself onto anti-oxidants, etc. as soon as I had any inkling of a problem. It gave me confidence to be able to go ahead in a way which seemed right to me.

Brett's diet was pretty rigorous. He said "Go and have a last lunch together and then start in the evening. And you have to do it completely. If you cheat, then don't bother coming back."

'So after work in Pukekohe, we went to a tearoom and I had one of those delicious custard filled fruit salad tarts. I remember it well as I appreciated every mouthful. It was to be my last treat for a long while so I wanted to make the most of it.

The diet consisted of rice and boiled vegetables for all three meals which was tedious. As well, I had to take a concoction of supplements and some herbal mixtures. After a few days, I was able to add a rice cracker with avocado and acid free tomato for morning and afternoon tea. How I savoured that! I lost weight, which was a real bonus, and started to feel much better in myself as a result. I was very positive. I needed the guidance, so I had the confidence to use this method of treatment. I had also managed to start on this regime before first seeing the consultant at the hospital and could tell him of something positive I was trying - not that they seemed to consider it so in the oncology department!

I must admit, though, it was difficult trying to prepare meals for Brian while having just the boring stuff myself. Often he did his own meals. The worst was when he was making a

delicious smelling roast pork dinner and I was having rice and steamed vegies! Still, I had to be strong!

A few weeks later, I asked Brett if he could let me have some contacts of other patients he had treated. He put me in touch with one woman and I spoke at length to her. She told me that her father was being treated and was doing very well. However, she said she also had breast cancer herself. Apparently she had got up from her second lot of radiation treatment just when they had been going to zap her - and she just went home. She felt it was wrong and she had had enough of orthodox treatment. Anyway, she gave me the names of some GPs who were interested in alternative treatments for cancer as I now had no GP, having parted company with my former GP over his lack of support unless I obeyed and trod the orthodox path. "Jenny" he had said. "What you need is to get your head round having a radical hysterectomy. That is the only way." I didn't accept that. But then, he hadn't accepted my concerns about the validity of my smear results. His track record on advice had not been good. He had been badly wrong about the smears. My intuition had been right. Why on earth should I trust him now?

I was able to get an appointment with a new GP, Ric, on the Saturday morning, which surprised me. He certainly gave Brian and me his time that day and listened carefully. Of course, he thought that a hysterectomy would be the best protection but did say that he could probably arrange just a simple hysterectomy. However, it would have to be done by an oncologist and they would only do a radical operation. I did not trust any surgeon once I was under an anaesthetic. Heaven knows what they would whip out! You can see, I now have little faith in the orthodox medical profession. Even if you find a competent surgeon, you are also in the hands of the anaesthetist and all the ancillary staff. It was just too much of a risk, I felt. However, Ric was prepared to support me in my efforts with

alternative therapies and made some suggestions. He also knew Mike well and often discussed medications with him. Ric has continued to be very supportive and I see him regularly to help me keep on track. So that was two people who could possibly help me. I was gradually gathering help around me.

The Psychic Fair



The next serendipitous event was meeting Dr. Chen and so learning to help myself by using Qi Gong exercises.

It was strange really. We had gone to a local Mind, Body and Spirit fair here in Papakura. We split up and wandered around the fair. It was the usual collection of stands. The general level of illumination was low, but there were lights on the different stands. Some readers were staring at tarot cards and then looking purposefully into the faces of their clients as they revealed what the cards supposedly implied for them.

At others, mediums of one kind or another would be conveying impressions 'from the other side', messages from 'loved ones', advice on life, love, children.....you name it. We'd seen it all so often in the psychic fayres in England. A few of the readers were genuine. Most were doubtful. We had tried for a while as readers. Brian devised his own Egyptian Tarot cards and was quite amazed that the people who came to him seemed to be able to relate to what the cards had said.

His first customer horrified him with her choice of card. They seemed to be all 'bad' ones. Brian had tried tactfully to refer to her being surrounded by darkness. Her response had been "Oh, that's my boyfriend. He is fascinated by 666....."

I did perfume readings. I got the idea what to do and how to do it. The women who came to me seemed to be helped by

the insight which was given to me - the ideas seemed to come into my head. I felt really quite sorry for some of the women who seemed to be in quite dire personal circumstances and did not know which way to turn.

I remember being very amazed after giving a reading to one young woman. It was clear she had to make a difficult decision to leave the relationship she was in. She came away looking sad and thoughtful and was pounced on by the man we called 'The Pimp'.... "My wife will give you a nice reading". This was the psychic version of "My wife will give you a good time."

There was so much shamming and conning. We got talking to one black girl on another stand. Her comment did nothing to cheer us up. We didn't get many clients, in marked contrast to the queues for others. This girl said "I used to be like you - trying to be honest and tell the truth. But you can't make a living. Now I just tell them what they want to hear. So they tell their friends to come too." It was probably the last psychic fair we did. Maybe our books are just a more long-winded version of the same solution and problem. Our books are true. They are just not what people want to hear.

I wandered further. There were people doing healing in the middle of all the psychics - different kinds of therapies, crystal therapies, scientologists, Chinese people, some dressed more as martial arts practitioners, all in white, others more normally dressed.

But was the healing any more genuine than the psychics? Doubtless some of them could make you feel things transiently, but was it real? I watched another woman with a crystal ball. She would be at home in a gypsy fairground. I pictured her amongst the throngs at Victoria railway station in London, handing out lucky springs of white heather to the rushing travellers and curses if they didn't thank her for her generosity with coins or a note. I could see her as something out of

Macbeth crossed with a caricature in some long-forgotten film “Cross me palm with silver....” Did these women really have any gifts at all? Had they ever? Was it all just a monstrous scam?

Oh yes, they all exuded sweetness and light but somehow emanating from a darkness. It was an odd combination which I didn’t altogether like. There was certainly little make me want to trust.

I trusted what came to me, what came to Brian, the signs, the little coincidences. But is true guidance really for sale to the highest bidder at the behest of these very doubtful fairground performers?

Other stalls had tinkling, psychic, wallpaper music to help create the atmosphere for meditation; another cure for all ills. I shuddered, for no reason I knew.

I met up with Brian. He had had a chat with a German stall holder who knew Diana. She was a German woman who had been the subject of much coincidence in July 1999. We had met her at a lecture Brian gave in Auckland on the Lockerbie disaster prophecy coincidence codes and the murder of Princess Diana. She was a practitioner of past life readings. She had come once to give us a demonstration at our home.

We decided there was nothing worth pursuing, no more future in pursuing promotion of our work in psychic fairs than there had been in England. It was very much the English style, no surprise as the organisers of these events were either English or had learned from those who were.

We had just emerged into the light of day when a man came over. “Hello, Brian....” It was one of the factory workers from the rendering plant in Tuakau where Brian managed the waste water treatment plant. Brian expressed surprise to see him at such an event. It didn’t seem to fit with the beer, rugby and sex interests of the ‘smoko room’ at the rendering plant.

“It’s the wife,” he explained. “She does psychic readings.

Come to check it out.” But this couple, too, were from England. Chris came from Manchester, just as did Brian.... Another odd coincidence.

We had each wandered round separately, looking at what caught the eye. I had not found anything particularly helpful, although I found a stand with Aura Soma colour therapy. I had always found colour helpful and, in fact, after that, I got out a large glass pyramid Brian had made many years ago. It has a revolving light under it, giving a steady progression of colour. I felt peaceful while relaxing and watching this.

We eventually left and came home. Brian had felt there was something there to help me but couldn't think what. About half an hour before the fair was due to close, he suddenly said that he thought it was those Chinese people in the corner so we went back. He had a treatment to see what he felt and was impressed. We made an appointment for him to go to their clinic in West Tamaki the following week, to check it out. I trusted his opinion of them.

It turned out that the clinic was run by a Chinese gynaecologist who has now retrained as a midwife here to enable her to work here in New Zealand as her qualifications, like most professional ones, are not accepted here. She had an acupuncturist and a Qi Gong practitioner working there several days a week. While Brian was having his treatment, I asked Colleen if she felt that Qi Gong could help me. She asked Dr. Chen and so I made an appointment for some treatments - twice a week for several weeks. The treatments were very intensive, involving deep massage as well as specific Qi Gong healing. I found them very beneficial. I was also given exercises to do at home and was taught how to use my mind for healing. All the translation had to be done by Colleen as Dr. Chen spoke little English.

All in all, I was starting to feel quite positive! The combination of my poor experience with the cone biopsy and the feeling that everything always seemed worse than I would have thought, plus meeting people who could help me in a practical way that felt good to me, meant I had the strength to continue with natural therapies. My supplement regime has continued, now guided by my new GP who is very sympathetic to my approach, although he does wish I could have had a simple hysterectomy - and so do I, in hindsight as it would have removed the bulk of the abnormal tissue and my body could have just concentrated on keeping itself well.

Or perhaps not - I don't take anaesthetics well and surgery is a huge stress on the body. I really felt I would not survive an anaesthetic and all the signs seemed to show this. Often, on drifting off to sleep, I would have the strong feeling of trying to stop being anaesthetised. As I am being wheeled into the theatre on a trolley, I could feel myself calling out in terror and Brian would come pushing through the double doors to rescue me. This vision recurred so often, unbidden.

Qi Gong has become an important way of life for me, giving me control over my body and pain. I have undertaken a couple of training courses in it so that I can understand the philosophy behind it. There is nothing nicer than standing on my front deck in the morning sunshine, listening to the birds singing in the trees, and going through my Qi Gong exercises. I come in refreshed and invigorated. And now Qi Gong meditation, too, has become part of my daily routine.

So, as Simon had said, I would find someone closer who could help me because he no longer could because he was so far away and often out of contact. Also I had learnt from my mistakes with him not to become too dependent, although this is difficult, given my history and my isolation. With Dr. Chen,

anyway, there was the language barrier as his English was minimal though it is improving now. And with Ric, there is the time barrier of a busy GP. However, I do value their support and appreciate that they go out of their way to help me.

Faith



While putting things in order which I felt I needed to do, I came across a letter from an old friend I had known in hospital in England in 1976. We had lost touch when my first marriage broke down and I didn't know her address. Yet here was a letter from 1985 just turned up out of the blue. I had no idea where it had been all this time. I felt I should write and the letter managed to arrive almost in time for her birthday in June. She was delighted and gave me family news. She still has many medical problems and life is not easy. While we were in hospital, I had got her to come to the local church on Sundays and she had since become a Christian. My own faith still remains strongly with God and we used to have many heated discussions on the subject. If I commented on healing, she would ask "Is it through Jesus? It must be through Him." "No, I would say. It is through God." She just could not comprehend the difference, although it is quite clear to me. Before I got her reply, though, my life had fallen apart with this cancer diagnosis.

9th October 2000

Dear Karen

It was really great to get your reply to my letter. So glad it managed to get there. I had put the church address on it and hoped that somebody there would

know where you had gone to. But it found you! Because it was meant to.

Sounds as if you, too, have had your fair share of troubles with health and family. Kids! They seem to expect to get bailed out when they mess things up! Mind you, Miranda and I have some very good mother/daughter chats.

I was interested in your comments about the disagreement with the pastor at the church. Sounds pretty un-Christian behaviour on his part to me. That is one reason why we just don't go to church. We do occasionally go to a lovely little early settler chapel near here which holds just 30 people. However the minister is just terrible. If you try to have a discussion with him, he just scuttles away like a frightened rabbit. And Brian is very strong and knows the Bible well and can out-argue even the JW's (Jehovah's Witnesses). This minister always shortens the hymns by knocking off a couple of verses but he catches Brian's eye when he does this. So, for the most part, we just worship God in our own way at home. But our faith is tremendously strong.

I am having to really live that now. The day after you wrote your letter, I was recalled for another smear test as the lab had lost my original one. That test showed some abnormality and I was put on hormones for 2 weeks and had another which showed high-grade CIN-III. I had been telling the doctor and the gynaecologist for 3 years that I had had laser treatment in England and that there was apparently still a problem and I was supposed to have 6-monthly tests. They just said everything was fine.

But it was not fine as it turned out. Anyway, all the bells and whistles came out and I was whipped off for a colposcopy (where they look up your fanny with a pair of binoculars while you're all strung up - really elegant!) and they did a punch biopsy. Apparently the Gynae could see something and said he was going to go ahead with a cone biopsy anyway and booked it for 10 days' time. I was most unhappy about this and in the end started bleeding the day before so couldn't have it done then - except that I stopped bleeding on the very day, but it was cancelled - just my body playing games.

Anyway, two weeks later, I was reconciled to this and had a cone. They made a right mess of it, not enough anaesthetic (local) so I nearly broke poor Brian's hand with squeezing it. Thank goodness they let him stay. Then they left a swab in and didn't tell me so I was very lucky not to get toxic shock although I was feverish and aching. It turned out, so I found out later, that I had bled heavily too so the surgeon could not go in deep enough. I had lost, he reckoned about 400-500ml of blood which is a hell of a lot for such a minor thing.

Anyway, the results of that came back on 6th September as invasive cancer - yes - a hell of a thing! They said the only treatment is a radical hysterectomy (uterus, ovaries, lymph glands, top third of the vagina - wouldn't leave much!) Or radical radiotherapy, including internal radiation.

I don't believe either would be the answer. Psychologically I don't believe I could cope with them and also the signs indicate that I would not survive. We work all the time on signs, coincidences, pointers.

Anyway, everything says that we should rely on God and not the doctors. I have to be very brave in this, even though I know in my heart it is right. But every time I see anybody in medical authority they try to persuade me otherwise.

So, I keep faith with God and am more joyous than I have ever been. I can see many of the reasons why I have this cancer and can see many of the things I have to learn from it. It is really tough on Brian, though, as he has no-one else. I feel OK. There are no symptoms and I am strong and vibrant, if a little scared. Brian gives me healing every day and I can certainly feel it. I, too, focus on the damaged parts and can quite clearly feel God's hand working on me. So, I just keep faith.

I know in my heart that if I give in to the radical treatments, then I can finish my life as I now know it, as soon as I go into hospital. This way, I have control and my health - at least for the moment. I will be well enough to do God's work that I need to at the moment. We are almost on the point of publishing. When that is finished, then I can go. However, if God intends my time on earth to be finished now, then so be it. One thing is for sure. Only God knows where each cell in my body is. The surgeon still doesn't know how much is left inside me, if any. Nobody can know for sure.

So, not good news suddenly from this part of the world, I'm afraid. However, I do feel really good and reckon I can survive, with God's help and Brian's strength beside me. I have made up a little song to the tune of "He lives! He lives! Christ Jesus lives today".

My Cancer Journey

I live! I live!
I'm living with cancer today
But I don't mind
For I will find
Ra makes it go away

I live! I live!
I'm living with cancer today
And here's the reason why I live
I live because of Ra

(Ra is our name for God, as we don't like the Jesusification of God although we do believe that Christ was the Son of God - but not God)

Anyway, I find I'm singing it in my mind, even if I wake up at night. I think it helps a lot and it certainly keeps my mind focussed on life.

Spring is wonderful here this year, although we have just had a bout of the equinoctial gales with squally rain for a week. We have tall trees on our section and it is rather scary. One big one came down in March of last year, but missed the new building we had just put up by a whisker. It hit another tree, sheared off a huge branch, was diverted slightly and came to rest on the corner post of the fence so that its weight was supported. All that a 90 ft tree did was break away a bit of guttering! It was God's hand indeed. Especially as the building it missed was our Sanctuary - a wonderful building built in the style of the old chapels here. This happened to be a garage which we took off the site and rebuilt. Brian made a

stained glass window and his sister wanted rid of some beautiful old church carvings from an altar screen. So we incorporated them and now have carved angels and a wonderful alabaster Christ. It is truly a place for peace and contemplation, looking out over the ponds and cascade we made in the garden.

The roses are about to come out. The wisteria has been fantastic - a wonderful pale purple and so we have lots of photos of that now. The jasmine smells terrific and the lemon and grapefruit blossom makes that end of the garden smell great too. We are very fortunate really. We needed almost two houses on one site to accommodate all our machinery for printing and binding books and also for our vast research library. We found one with what they call a "sleepout", already carpeted and we built the extension on to the back of that. We have some of the original old farm trees in our town and I love it. The first owners of this house had planted trees out the front too - a silver birch, golden elm and silk tree. These are all deciduous and give shade in the summer but let the light through in the winter. This year I am cultivating the garden of the man next door so I can grow my own fresh vegetables. Our garden is too shaded. But it works out well. He can take what he wants, as well as for his elderly mother. I enjoy the work and the only problem is the watering which is desperately expensive here now with privatisation which we fought tooth and nail but which the apathy of most people allowed through.

Anyway, hope this letter finds you all in good health and happiness. It is strange that just after

managing to get back in touch and the delight of receiving a reply, that I ended up with such bad news. Still, there is a reason for everything. It was lovely to hear back from you. Please keep in touch.

I may be slow responding at the moment as the round of doctors is getting stupid and I am trying to keep up my part time job too to pay for all the supplements, vitamins, doctors, etc. Yes, it was a real pain. I got a job just after I wrote to you. I had finished all my accounts and said to a friend of mine, who works at the same accountant where I had worked some years back, that it seemed crazy that I could do all that and couldn't get a job. She asked whether I wanted one as she knew of one of her clients who needed someone. It was in a gym and she didn't know if it was my thing. I contacted them immediately and they were interested. It is quite good. I get free membership of the gym but had to have the cone biopsy only 4 weeks after starting so had to stop all exercise. However, I am back again, although trying to find the time is difficult. Also they have a sauna which will be good for me. I go down about 3-4 times a week (15 hours in all). It is a pleasant drive through the countryside to a nearby town and the people are very nice to work with - mind you, I pay their wages so they are extra nice to me!

I am trying to keep up with that work, do our own accounts and taxes and find time to type Brian=s books as well as learn what I can about cancer and treatments and do all the things I have to, like finding quiet time to visualise and cooking vegetarian meals which is quite a challenge. So, if I am slow in replying, please bear with me. This letter

Jenny Cocksey

has been sitting half done on my computer for a week now!

Love to all and take care,
Jenny

My faith in God is probably the most important element in my healing. I have an unshakeable faith and trust in the guidance we receive through coincidence. There was a wonderful sign up in front of the Anglican church in Tauranga when Brian went there on the first contract of our new business - Coincidence is God's Way of Remaining Anonymous. Every single visit to the hospital gives coincidences which warn not to have surgery. Brian gives me healing regularly and I can certainly feel it.

However, I do know that if God intends me to get well, I will. And if He has decided it is my time, then I won't. And that doesn't matter how many treatments I have. It doesn't mean, though, that I can just sit back and wait for God to cure me. Far from it. I have the responsibility now of undoing the damage that has obviously been done over the years to my immune system which has allowed the cancer to develop. This means making sure that I help every system in my body to operate at its optimum. I need to really concentrate on finding out how my body works and do what I can to assist. And most of all, I must change my thinking. I must find joy in life, not get stressed and worried, relax more and love more. Only in this way will I be able to heal. I am doing my best.

And every day I thank God that I am still well and in better general health than ever - both physical and emotional. And I have a real appreciation of life. I laugh and sing and feel at peace, especially in the light of Ra in our garden.

In our exchange of letters, I recently wrote to Karen, who

is ill with severe, chronic depression, that it is ironic that she wants to end her life and I am struggling to keep mine.

We each have our faith in our different ways. She is "born again" and wants to go and be with the Lord. I feel I have work to do here and need to be as strong as possible to carry it out and that God will take me in His time.

Be Positive



Brian's sister had phoned from England while I was on a long phone call to the other patient of my homo-toxicologist. This was a really helpful call to me, but Val just wanted to speak to Brian about something and was impatient that I was on the phone so long. We have "call waiting" and so her calls would come through and I had to interrupt my call which was frustrating for me as well as for her. Brian got very angry with her at this because I didn't need to have people trying to push their point of view on my treatment. She was insistent that I should have a hysterectomy and pushed and pushed. It is hard enough having to stand my ground with the oncologists. I felt I should write to explain to her why her brother was angry. I really didn't want upset family relationships. I felt I wanted calm and peace around me. This is typical of the way people have really fixed ideas about cancer treatment - mostly centred round going the orthodox route - and mostly based on fear. I found it very difficult.

9th October 2000

Brian is writing you a long letter in the bath - the place where he thinks the best. You are his sister. You and Fiona (Brian's daughter in the UK) and I are the only people left in the world that he cares about.

At this point in the letter, Brian called out that he heard a steam train whistle. I dashed out, grabbing a skirt and shoes as I went as all I was wearing was my T-shirt & knickers for comfort. To our amazement, there were two steam trains in the station and quite a lot of people watching, especially old people reminiscing. After all, Papakura was where the army camp was and for so many of the soldiers who fought in both world wars, Papakura Station was where they got on transport to take them the troop ships and then overseas, perhaps to their deaths. Now, like so much, it is almost desolate. I saw the steam trains as an echo of the past - we have never before seen two steam trains there.

So it was very strange that this should happen this morning. We would not normally have been here. We had intended to go down this morning to Brian's last remaining half day of work in the week, dropping me off at work on the way to save taking two cars, but instead, as it was a beautiful morning, Brian was going to spend it finishing off a machine he needs and then go this afternoon when it often gets cloudier. He had also noticed the water meter (which he reads every morning and which often gives links) had gone to 5577 (remember heed or perish - part of our Coincidence Coding system). He had shouted to me not to use any water and so I had started your letter instead of doing the dishes. That 5577 was very significant. Remember I told you about it at the hospital, referring to my not having radical treatment? These are the ways we make our decisions on major things, as we have tried to explain.

Anyway, to get back to the point of this letter. I was really sad last night when Brian got angry with you. I loathe discord and it is very bad for me. I must try at all costs to keep calm and not let things get to me. But I hate family splits and aggro. However, I can see why Brian gets angry. It is quite endearing really that he has so much of a protective feeling for me. He gets really hurt that people don't seem to care or acknowledge what I am going through - including my own family. And, of course, people forget that he, too, is going through anguish at watching me try to come to terms with all this.

With Brian's help and guidance I have reached my decision about no radical treatment. He steadies me when I am shaky. He encourages me. He gives me healing. He helps me stick to a strictly disciplined life and diet. He does everything in his power to help me stay well. And he gets very angry when I am not taken seriously - which is why I am in this position in the first place, because the doctors didn't bother to listen to me and follow up as they should have done.

There is a report in the paper this morning of yet another case where a woman had similar treatment to me in the earlier stages and now there is a legal case against the doctor. I cannot afford to take a legal case and nor do I want the stress and strain of it. It is all just so unjust. They are still there, getting their fat fees, while we struggle to even afford the medicines I need because of their incompetence. However, with clever lawyers and the might of the protected medical edifice, it is almost impossible to win - and the struggle would no doubt exacerbate my condition.

Brian was firstly angry at your irritation that you couldn't get through on the phone just when you wanted to because I was using it to talk to someone about cancer. I do not normally spend so long on the phone. However, I had phoned the daughter of a man who has a terminal cancer and is being treated by the same man I am. She was very helpful and kept telling me all sorts of encouraging things.

She had had cancer herself 10 years ago and after some conventional treatment, decided she couldn't trust them for a further bout of radiotherapy and just got off the table just when they were about to operate the machine and discharged herself. When they checked the scan a month or so later, they could find no sign of the lymph node involvement which was why they were going to do the radiotherapy in the first place. So she was justified in her extreme reaction (which, incidentally, is the same way I feel. Every time I come round to thinking about it, I find myself in a dream sequence of tearing the radiotherapy holders out of my insides, or tearing the needle out of my vein just before the operation and bolting.)

She felt very unhappy about the treatment - just as I do. Maybe it is illogical but it is important to listen to your body in these circumstances. She confirmed that for me. And her father was told to go home and die. Currently he is beating all records, she said, for certain aspects of his condition and is fit, healthy and able to mow the lawn, etc. He is using the same regime as me, with the addition of specific things for his particular cancer. He is 76 and his wife has difficulty preparing the special things for him -

but they all pull together as a family and he is doing really well.

I am more fortunate in that I can adapt my cooking more easily. I can have no dairy, no meat or chicken, no wheat or wheat products, no fats except for olive oil, no tomatoes or potatoes, etc. So, it does limit me. And it all must be organic which is hard to get hold of. So I now am cultivating the vegetable garden of the man next door so that I can grow my own organic vegetables. However, that takes time, although it is very therapeutic for me. Brian doesn't have the time to help much and the damn cats dig it up. However, it will provide a good source of controlled food - as well as the exercise, fresh air and the necessary satisfaction in life to keep me going. I used to grow all my own food in England in two allotments.

So, it is possible to live a good quality of life, even if damned by the medical profession as having cancer and then being about to die unless you use their treatments. Yesterday I had to go and see a skin specialist I had seen before when he lasered some wart things from my hand and some growths from round my eyes. He was very positive and agreed with me about my theories about the immune system. He was really supportive. He deals with cancer patients, especially older people who may have to have some disfiguring treatment. He agrees with them when they ask why they should bother. Anyway, it was good to have support from a doctor. Mostly they close ranks.

We had an example of that this morning. We were supposed to talk to the radiologist who did my

last MRI scan. Suddenly he doesn't want to talk to us "You must speak to the specialist or your GP." However, they can't read these scans either - they have to just go on a two-paragraph report. The specialist tried to interpret the films for us but couldn't. They are totally dependent on these scans or lab reports and it is these that we dispute. On Friday, the pathologist couldn't even work out exactly where in my cervix the samples on the slides had been taken from because they had been done by a different lab and not labelled adequately. It is an enclave of protect yourself and your doctor mates. I don't want any part of it. Once ensnared, it is almost impossible to escape.

And as for life and death. We all have to die of something, sometime. I don't know if I am meant to die yet. Nobody knows that - only God. I will go at a time of His choosing and in a manner He chooses. Yes, often I have wanted to die. That is because life has often not been worth living - with pain at seeing Brian so hurt and frustration at getting nowhere and seeing him being thwarted at every turn. However, I have been kept from such an extreme step - and I feel it is wrong, anyway, to take your own life. "As thy strength, so shall thy days be" is in a frame hanging above my photocopier.

However, I do know that if I can continue in relative health and strength for a bit, I can help Brian to achieve what he is on this earth to do - namely warn. I know you don't go along with it, but the signs become ever stronger. That is why he has been given all that he has. Nobody - or few - will take any notice. Nobody ever -listens to warnings. However, the

legacy he leaves will be a warning to man - and woman - of the ways of the world and the consequences of not changing radically.

I may only have a couple of years before this takes me over - and it wouldn't be a pleasant death either. However, I know it is the right decision and I trust that I will be given enough time and strength and that I will not suffer too much at the end.

On the other hand, if I submit to radical treatment, I cannot predict the outcome. Surgery would most likely kill me. All the signs point to that, independently of the fact that the last time I needed surgery, they wouldn't give me a general because of the risks but just blocked the sensation in my whole arm so they could operate on my finger. Also, I am not healing very well at the moment - either from wounds or burns. The skin specialist looked at my finger again yesterday which has not healed properly in over 6 months. He agreed that if tough skin on the outside can cause that much problem, I don't stand a very good chance if my tender insides are burnt (which is what radiotherapy does).

In either scenario, I would be weakened considerably - to the point of being unable to work at either my paid work or on the writing, or even look after myself or Brian, for at least 2-3 months. Even if I survived surgery, there would most likely be severe side effects, such as damaged bladder which would require further surgery or make my life very painful or difficult. The same goes for radiotherapy, even if I could trust them to give the right dose - and I don't trust that particular specialist. He couldn't even tell us the truth. I feel it would be the end of my life as I

know it now. And it would be like committing suicide (probably slowly) in 3-4 weeks time. No!

Brian got angry with you about your irritation that you couldn't get through and your pushiness over a hysterectomy, though I can see you are concerned for me. I switch off from anger. I have to if I am going to survive. People keep telling me what I should do.

And when you started on about me having a hysterectomy again, he just lost his cool. I cannot allow myself to get angry. But Brian gets angry for me, I suppose. And I love him for it, even though it distresses me to have bust-ups. I felt genuinely sorry for you. I need positive support, not harping about what the medics, friends, you think is the best way.

Even my parents respect my decision enough to not have a go at me. My father sent me up a juicer so I can make the fresh vegetable juice I need (which I tried for the first time today). He also sent me some bottles of colloidal silver which could well help me. My mother is more negative but at least she doesn't go on about a hysterectomy. The only reason she thinks I should have one is that I may not be able to afford to continue with the natural therapies - but I will find a way, somehow. I hope you never have to make such a difficult decision in your life.

Who knows what they will do in any given situation. You hate hospitals - wouldn't even go when you cut your face and a stitch would have the logical treatment! What would you think to having most of your insides cut out, your bladder damaged, and possibly your bowel, to be left with probably permanent severe pain and disablement, to the complete dependence on someone else for

everything for several weeks, to the inevitable depression and loss of will to live, to living with swelling in the abdomen and legs, to the loss of a goodly portion of your vagina? That is what we are talking about.

And it is not that I am even sick. I am better and more vibrant now than I have ever been. It is not going to relieve any unwellness I feel now - merely make it a hundred times worse. I know the risks. I also know that the mind is very powerful (and this was corroborated by the skin specialist yesterday who said that this is a very valid form of medicine and that the mind can play a very important part in the state of the skin - and after all, I have squamous cell (or skin cell) carcinoma of the cervix).

I know that with Brian's help and above all with God's help, I will have the strength to get through this, to hold off the worst ravages of the cancer, to continue for long enough to do what I must do in this world. Even now, I am working hard. When I had finished that telephone conversation at 10.20, far later than I had ever thought, I continued typing chapters of Brian's book until about 12.30 before talking a bit about you, having healing from Brian and then going to bed about 1.30 am.

We work every waking moment, often doing a couple of things at once. No - I am not trying to say we are superman and woman. I am merely trying to show that we have such a purpose in life, such a shortage of time and resources, that we must not waste any time. You see, Brian was getting on well with his work last night. But he knows that every time someone has a go about a hysterectomy, it throws

me off balance, it causes me to waver a little, for the natural fear to well up in my tummy instead of the joy and confidence I am starting to feel.

Yes, this has been a liberating experience for me. For the first time in my life, I have a say about MY body and MY life. I can converse with authority in the form of the doctors and they have to listen to me - especially because it is the actions of some of their number who have allowed this situation to get to where it is now. There has been gross incompetence, negligence, lack of care, lack of listening, etc. and they all know it. I feel in control, confident, joyful almost, with a strong sense of purpose and going forward to make the rest of my life count - every single day of it. That is a truly wonderful experience. And even if I only have a very limited number of those days, I intend to make them all good ones, all doing what I can to help Brian and to reach my own destiny.

Maybe you can't understand that sentiment. I must admit that I am surprised at the way I feel. And when we decided on Thursday that I should have the hysterectomy after all, I was relieved and decided that it would be better to get it out of the way. It was the sixth anniversary of our arrival in NZ and we went up to the hospital chapel and looked out over Cornwall Park and One Tree Hill (an Auckland landmark). My parents had taken us up there straight from the airport. We thought maybe it would be a new beginning to have the operation, get over it and then get on with life. I wrote in the book "I will lift up mine eyes to the hills, from whence cometh my help."

However, that evening, even though I was fully

accepting of the operation, I started to lose life, felt completely resigned, gave up almost. I was bothered by this. All my new vibrancy disappeared. And when I went to bed, I became almost hysterical about the operation. This was entirely a body/mind reaction - not what I was logically thinking at all. Brian reckons that is how I would feel after the treatment. We then decided it was another sign against it and by 24 hours later, I felt vibrant, positive and alive again. More signs, you see!

Anyway, I hope you have managed to read this far without getting too angry. I am trying to explain things to you. I don't know yet what Brian's letter says. He has gone to post some samples before we have a quick lunch and then go on down to work. This has taken me almost two hours to type. However, it is important for you that you do try and understand where I am coming from.

You also said the other night that he was wrong to want to die. He is not afraid of dying, although I suspect you are. I spoke to a close friend of ours who has been helping me for years with grave problems stemming from my childhood, helping me to come to terms with life. I asked him why I had had such differing reactions from people to my cancer. He explained that those who gave the worst reactions were those who had not come to terms with death themselves, those who were afraid to die. It seemed to make sense - especially when I think about the different people concerned. Anyway, Brian would never presume to take his own life. But he does despair so often that he will ever get anywhere. You say he is a depressive. If you had been knocked back

in life as often as he has, you would despair too.

Just think - he lost so much - and all from the actions of other people and the actions of lawyers. But since then, he has gained an understanding of God, much knowledge that is given to few but which he has earned because he makes an attempt to understand - and he has gained a new wife. And companion. Now it seems he may lose his wife. He is unable to put out anything to the wider world. He is thwarted at every step. He cannot fight as he has inadequate resources. In fact, he can barely function in the world at all because of that same hindrance.

Yes, we can manage for a bit. But time is of the essence. He has so little time and energy and so much of it has to go into repairing old equipment, maintaining the old cars so we have transport, scratching a living..... And we are tired, so tired - both of us. It would be easy to lie down and die and so often we have both wished we could. However, we must both keep going - and we will - until our work is done.

I do believe, as I said before, that we will not live to see the fruits of our labour. So many men in the past who have had new ideas and have made contributions to man's knowledge have not lived to see that. They have died first, worn out with the struggle against the establishment and power. When Brian says he wishes to die, that is what he means. He is so tired, so disillusioned, so frustrated, so hopeless..... And it makes it so much harder when you phone and tell him how good life is, how much your flat is now worth, how you are going to have a sea view (how often he says he wishes he

had a view), what your next holiday will be (when he is so tired). It is not jealousy - just resignation. We struggle with so little - yet somehow, we are always helped to keep going. And we have each other. And we have God.

For some reason, my illness has brought a lot of things to a head with a lot of people - something I find quite distressing. However, one thing I do know from experience - Brian is usually right, even if it may not seem so at the time. And I have learnt the hard way that it is better in the long run to take note of his guidance, however unpalatable it may seem at the time. The guidance comes from a Higher Source than he. Brian is merely the messenger - but so often it is the messenger who is shot when people don't like the message. Don't make that mistake - the same that has been made throughout history.

This may seem somewhat philosophical. However, it is my determination to be able to continue helping Brian with this work which gives me the strength to overcome my tiredness and continue with my struggle.

Brian's sister is very much of this world and just does not understand her brother's work, although she does try to help him by gathering newspaper cuttings and getting books for us from England. They are so different. Strange to think they share the same family background!

Val exhibits the traits of so many people both to cancer and to our work. It makes them afraid. With cancer, it brings the spectre of death that much closer to home and makes them think about their own mortality – a subject which scares many people. And with our work, this also makes people afraid and they will do everything in their power to try and find any other

reason but God to account for the many strange and wonderful things that happen. If there is truly a God who can so fine-tune things so as to orchestrate these coincidences, where does it leave them? It is not a comfortable thought for many people, especially the rich and powerful who think they can do as they please because of their position.

I think deeply about all sorts of matters. I strive for an understanding and for the truth. This helps me in this journey with cancer and gives me a purpose in my life. And my deep faith means that I am not ultimately afraid, whatever the outcome may be. I know that I will have followed my destiny.

Joyous !



Over the next month, I gradually got myself together and actually became quite positive. I almost had a sense of elation at the task ahead, strange though that may seem. At first my anger at the system had kept me going. I had spent the first couple of days phoning round, trying to see where I could get help, trying to see if there were a purpose all this. I found that there was no support from anywhere official. I tried to interest the press as it seemed as if it wasn't just Gisborne where there were problems with the cervical screening. After all, I had had six clear smears in Auckland and now suddenly there was invasive cancer. What had gone wrong? However, the press was more interested in Colleen Poutsma in Northland and the women in Gisborne.

It didn't matter. I read up what I could. I searched the internet. I tried to get on with life and with helping myself to get as healthy as possible. I found the reactions from friends and family rather confusing. Our closest friends pulled away and didn't communicate at all. When Brian raised the subject with them, they said that they were expecting to come to my funeral next. I found it all rather distressing. Yet, somehow I managed to rise above it.

11th October 2000

Simon,

I hope you didn't get hurt or angry by my comments about you. Actually, Brian said a couple of days ago that Simon has been the only one of our friends/relatives who has come across at all well in this sorry saga. So! It's just that my expectations and needs are too high. Mind you - I am getting better. There is nothing like cancer and being faced with death to get priorities sorted out.

Simon, I cannot understand my feelings. I am so positive, enthusiastic, optimistic and actually joyous - yes, that is the only word for it. I wouldn't have thought these were appropriate feelings at this stage, only five weeks after diagnosis with a life-threatening disease. However, it is though a huge cloud has lifted from me. It is as though for the first time in my life I am truly free to be me. It is quite liberating - and puzzling too in some ways. Yet in other ways I can see what is happening. I am in a position where I can determine the course of my life, as much as anyone can. It is my body and my life and I am being given an opportunity to say what will happen to it. In spite of heavy pressure from some quarters to do the orthodox thing, I feel safe and secure in my decision (most of the time). I feel freed from authority. They can't MAKE me do something, can they? I worry about the time you said you would have sectioned me to make me go into hospital. They can't do that, can they?

Anyway, I don't know what it is. But I am changed somehow. I am calm, reasonably relaxed,

positive and disciplined in my life. Brian and I are getting on so much better. He is doing everything he can to help. And he has radically changed his outlook and diet too. So, some good may come out of it all. I can now turn away from food which might harm me - in fact, I actively don't want some things now. In the same way, I can turn away from emotions and people that will harm me. I can almost feel myself turning them aside like the bow-wave of a boat. It is actually a very uplifting feeling. I have made up a little song which I find myself singing all the time, even if I wake up in the night and it is so positive.

Simon, I will beat this. I know I can. But I also know that I wouldn't have had this understanding and this ability to cope if we hadn't done all that work together for those three years. I started to understand so much - and now this is accelerating that. No matter how much or how little time I may have left, I know I can now use it positively, joyously, productively. I can't tell you how happy I am! You need to see it for yourself. Instead of throwing my arms round you in fear and for security, I would now throw them round you with joy and acceptance. I wanted to tell you this. Yes, I still hurt at friends. But it doesn't matter. It seems to matter more to Brian than to me. I have now accepted my aloneness.

So you see. There are a lot of changes. And most of them are for the better. I do not know how long I have - or even if I will die of something else like our cat, Sooty. (Incidentally, I forgot to say in the last letter that I got my diagnosis on 6th September, the same day that we refused to have Sooty have a hysterectomy - the day of Diana's funeral. We used

homeopathy with her and other remedies and she made a full recovery and died of something else a quarter of her life further on.) Only God know each cell in my body. The medics don't seem able to answer any of my questions.

I looked at my slides on a TV screen in the path lab last Friday. Definitely cancer there and definitely incompletely excise. It was really fascinating to see all the cancer showing up as dark blue against the pink of normal tissue. It certainly brought it home to me with a bang. It was so obvious. (However, the pathologist couldn't even tell anything about the tumour - volume, position, etc - because the original slides weren't very well labelled. The radiologist who was at first friendly, won't talk to me about the MRI scan where he reckons he can see a further 20mm shadow up the canal to the uterus.

However, the consultant is being really helpful and actually listening to me and said they often get false positives. He and Andrew have both said that perhaps it has actually all been removed in the cauterisation process as this will damage all the edge cells.

I spoke to my skin specialist on Monday about the wart things on the backs of my hands and asked him that if I could make them go away with my treatments of the immune system, would that be an indication that I have brought about the same changes on the inside. He was very positive about the power of the mind in medicine. So there is a mixed bag of responses.

However, one thing is clear to me and that is how doctors close ranks against patients whenever

patients ask for more information or query things. That doesn't make me feel safe at all and doesn't make me want to put myself into their hands again.

On Thursday, which was the sixth anniversary of our arrival in NZ, I managed to talk to the consultant and the radiologist about some of the deep psychological reasons why I couldn't accept radical treatment, especially radiotherapy. However, I immediately changed from being positive and bubbly, to withdrawn and unable to communicate. Brian and I went up to the chapel at the top of Greenlane where there is a wonderful panorama of Cornwall Park and the obelisk which was shining in the sun. We had noticed it from the motorway on the way in. That is the first place my parents took us on that day when we arrived - for old time's sake. So it was odd. Anyway, we decided that perhaps I would accept surgery and that it would be better. I was very positive and felt quite relieved in a way that it would all be over and that maybe it was a fresh start.

On the way home, I was very withdrawn. I had been quite positive but suddenly my mood changed again. I felt I had failed by giving in. I felt all the life fade out of me. I also felt myself just handing over my life to them. The mood persisted and at bedtime, I suddenly collapsed and was wild, thrashing about the bed. I don't remember much but eventually Brian calmed me and I went to sleep.

The next morning, he said he thought maybe that is how I would feel if I had the treatment - totally defeated and withdrawn from life. I was pretty low when I went to see the slides that morning, very withdrawn.

However, by evening, I was full of bounce again, digging next-door's garden to plant my vegetables, singing in the rays of the setting sun, truly understanding the part I had played in all this and accepting it. And then I was ready to go forward. And I haven't looked back really since then. Yes, every time I have to deal with doctors or pushy people, I get a mild attack of anxiety. But it soon goes.

It doesn't matter how long I have left. I will treat each day joyously, see what it has to offer. So each day brings something new, something to learn. We are getting on now with our lives and our writing. I will have time, I know, to help Brian get things out. What happens after that doesn't matter. I guess neither of us will live to find out. But maybe we will! Only God knows that.

I see now how wrong it was to have been so saddened by the world that I wanted to leave it. I want to stay now, to be here to truly help Brian. I can see how low he gets when he thinks of losing me. Please, Simon, if that should happen, would you please keep in touch with him from time to time - please. It is important to me.

It is an adventure. Sounds a strange way of looking at things. Yes, I am a little anxious about the manner of my going. I hope I can remain well for a long time. But I am not afraid to die - it just seems a waste when I have so much I want to accomplish, so much I want to learn. Well, I wasted many opportunities, so I must make sure I live every moment I have left to the full. Thanks so much for your part in my life. I know I sound ungrateful and harping some of the time. But I truly appreciate it and

Jenny Cocksey

know you have little time to spare. It's just that I am so needy some of the time. I am glad you find time to think of me and write. I really look forward to your reply and to perhaps seeing you again soon so I can show you the joy I feel in my life.

Take care of yourself and I hope the family are all happy in your new life. By, the way, I don't mind if you tell Susan. I have warned many women to be wary of the accuracy of the smear tests and that if they have any doubts, to insist on a retest. But in spite of its failings, I am glad that the screening programme exists. It is just a shame that it lulls with a false security - like so many things in today's world.

Must fly. Please keep in touch as much as you can. I do value your input. I miss you and being able to come to you for an honest response to my worries. Take care.

PS:As usual I have gone on. This was only meant to be a quick one-pager. I don't get any better at brevity, do I? But you are a master of that!

Jenny

Into the System



1st November 2000

Well, I finally had the cone biopsy. And, as I had feared, it was cancer - and poorly differentiated at that, which is the worst type to have, apparently. It is more likely to grow fast. What to do? I spent quite a bit of time scouring the internet for information. It all seemed bad news. The only thing that really struck me were reports of women who were diagnosed during pregnancy. It seemed that if they were allowed to have their babies before a hysterectomy then they had an excellent prognosis as they had something to live for. Of those women who had had a termination and hysterectomy or radiation treatment all together, none survived. There was probably no point. I found that interesting.

I am no doubt one of those notoriously difficult patients that I have since found out are more likely to do well, one of those who questions everything and won't just do as they are told by the experts. However, by standing my ground, I was able to find out a lot more to help me make my decision.

I was referred to National Women's Hospital Team and found the consultant thorough and sympathetic and I had confidence in him. In fact, he became what I referred to as the >human face of the system= and I felt at ease with him.

However, I was in no rush to have surgery. My experiences to date had given me no confidence at all in the System.

Could I not have a simple hysterectomy? That seemed to make sense, given that they might have actually got most of the tumour with the cone. I was definitely against having all my glands taken out. But no - it was all or nothing. However, he did say that he would try and make arrangements for an MRI and also for me to see my slides.

The MRI was quite scary, especially as the whole bed in the machine suddenly became red hot. They had switched the microphone off and it was fortunate Brian was in the room with me when I called out so he could alert them. At first the radiologist was really helpful when I went to pick up the films, stating that my consultant was right and that the cancer did appear to be creeping upwards towards the uterus. I arranged to have a meeting for him to explain the films to me, but suddenly it was not possible and we came up against a medical brick wall. Ranks suddenly closed.

We left a message for a radiologist acquaintance Brian had met through bookbinding and who also knew me. All we wanted was to ask him to help us by explaining a bit about the MRI films. When we had phoned and left a message for him to call back, we hadn't told him what we wanted or what was wrong with me. But when he phoned back, he had obviously looked up my notes on the computer system and was quite abrupt, saying that if it was his wife he would insist on her having surgery. I felt that this was really an infringement of my privacy. He had had no right to be able to have access to my information like that. And he certainly didn't have the right to force his views on me when I hadn't even asked him.

The meeting at the hospital laboratory was very useful and we were able to see very clearly, magnified on the screen, the cancerous tissue in the removed cone section and the normal

tissue - quite fascinating really, if I remained just a detached observer. The cancer showed up as a dark blue whereas the normal tissue was pink. It certainly brought home to me the fact that there was certainly cancer in the cone biopsy they took. It made it real.

I asked the pathologist to explain from the sections he had precisely where the cervical canal was. He had various groups of these sections, each with two channels. I asked him to explain which was the cervical canal. His reply was that maybe one of these sections was taken off another slide - for economy? I was concerned, though, that he could not explain how the sections related to the original cone, nor could he explain how the two tumorous areas relate. It bothered me. I had really needed to see the cancer in relation to its position in my cervix so I could visualise it better, a three dimensional approximation of the size of the tumour removed. This way I couldn't really visualise where the cancer was in relation to what was left of my cervix and in comparison to the cone I had seen sitting in its jar of formaldehyde shortly after it was removed. However, Brian took some photos of some of the slides which was a help.

The most disturbing thing in all this is that surgeons have to rely on the reporting of test results to make their diagnosis and determine the best treatment. However, all our attempts to get more information other than a minimal few-line report have been fruitless. The most obstructive people are those on whom we all have to rely for accurate information. If they are unwilling or unable to give clear explanations of how they have arrived at their conclusions, then how can we trust them?

The response seemed to be universally that it doesn't matter where the cancer is as they are going to remove it anyway. I was not at all sure about that. I needed to have information on my body so that I could make a truly informed decision. I needed to see whether this was something really fast

growing or just a slow progression of an earlier problem which just had not shown up in all the smear tests. This was important information for me to help make a decision. But my body seemed to have just somehow become the property of the state. My cervix no longer belonged to me.

I tried to have my slides reread in Australia. The upshot was that I was given two differing stories. Firstly I was told that they were waiting for the Health Funding Authority to agree to readings being done outside New Zealand because of the problems of reporting on colleagues. This would be like waiting for doomsday, as the HFA wants to sweep all reference to mistakes in the screening programme under the carpet. Nobody from there had ever come back to me when I phoned them.

However, the Sydney Laboratory of Douglas-Hanley-Moore was willing to re-read the material for us, free of charge, if we arranged to get it there. But we were unable to get hold of my slides. The local laboratory refused to release them 'for medico-legal reasons'.

In a further meeting with the pathologists, we were told that it was up to the Australian laboratory to do all the organising and get the slides from the lab here. It was stalemate and the coordinators at this end faded away. Do I detect the unpleasant smell of a cover-up by New Zealand so-called >professionals=? Are they just trying to force me to comply with the wishes of the medical profession to hopefully cover up another grave error in the cervical cancer screening programme?

I kept being told I will most likely to die of the disease. This made me really angry. I may die or I may not. No one knows the real status of the disease now, although my consultant indicated that he is willing to help me to monitor the situation even though he would prefer me to have surgery. I am not doing >nothing=, although the medical profession would no doubt choose to view it in that light. I am taking

strong measures to follow a course of treatment which is in conformity with my beliefs, ethics and understanding.

There seemed nowhere to turn within the system. Doors seemed to close unless I was prepared to just go along with what they wanted, what they decided, in their wisdom, was best for me. No doubt they were trying to do their best. But I needed to be sure, and I certainly needed to have a say, make a truly informed decision. After all, it was my life and my body. The decision I made would probably be the most important of my life.

There seems an accepted order of doing things, regardless. Woe betide anyone who goes against the advice given, even though it is given in good faith and to help the patient. However, I did feel I did not have all the information, even though they had been very helpful in letting me see the slides, etc. But it seems that things must be done according to the system, or not at all. This left me with the choice of not at all.

At present, I am more distressed at the withholding of information and the unwillingness of doctors to explain as much detail as they can than I am at the cancer itself. Everything is fobbed off and all I get is more pressure to have a hysterectomy. Every time this happens, it is one more nail in the coffin of the medical profession, as far as I am concerned. I am coming to trust them less and less as each request for information or an explanation of test results is stonewalled.

Tonight I have become quite depressed as the fear engendered by this response has all got on top of me - and also as I am becoming suspicious about even whether the cone biopsy was done properly. That is the final straw. I need to be able to keep up my bouncy, positive outlook to give myself a chance. Would that the doctors would help with this approach instead of sabotaging it at every opportunity.

I do feel that a hysterectomy would be wrong for me

because of a range of things which have happened to me. I have discussed these with the psychiatrist at the hospital who agrees that my decision is reasonable in the circumstances. I feel that the risk of radical treatment, either surgical or radiation, is greater to me than is the risk of this amount of cancer which, although a threat, can perhaps be held at bay by my own strength of purpose and determination to overcome it. If not, so be it.

However, the proposed radical treatment would remove all of that strength. I have had this shown to me already. At least I will have had some time where I am healthier and fitter than I have ever been in my life in which to accomplish what I feel I need to. Better that than living as a shell - if I live at all.

This is not a decision I have taken lightly. I have thought of little else for the past few weeks and have explored every avenue. Naturally I am sometimes anxious - but would I be any less anxious if I accepted radical treatment? There is always the risk that the disease would still be there - only my body and mind would be less well equipped to fight it.

But for me to successfully fight the cancer and win, I do need as much information as I can get so that I know exactly what I am up against. However, it does seem that I am first and foremost up against a closing of the ranks in the medical profession which prevents me from finding out the information I need to. This is singularly unhelpful. I thought doctors were supposed to "First do no harm". However, this approach is very harmful to my wellbeing and ultimate ability to get completely well. It does nothing at all to restore the faith I once had in the medical profession. It pushes me ever further and further away.

I do have trust in the consultant and am grateful he is willing to continue to monitor me. I do need to know as much as I can about the state of my cervix - but my mind and the rest of my body are also important to me. For me, it is not a question

of life at all costs but of a quality of life for the time I need. I am fully aware of the situation as it is put to me. I do not trust much of the information I am given because it seems to come from rather doubtful reporting.

However, I agree I had cancer in the cone but am not sure how much is left - and nobody can be. I am taking active steps to build up my strength and my immune system and to heal my body in every way I can. And I will overcome this obstacle in my life - and most certainly am learning from it and gaining strength from it. However, if it is my time and the way I am meant to go, then that is for God. However, I will continue to do my best and to make the most of my time.

I have since learned, from my wide range of reading, just how impossible it is for the medical profession to take alternative treatments seriously. It is a shame, because with active cooperation, I am sure the outcome for patients would be much better. Even if they don't survive, what is left of their lives would be more positive. I am sure that it is better for somebody to be following a course of treatment they genuinely believe will help rather than something foisted on them out of fear. It is important to really seek out what is best, then ask, and ask again. After all, it is your life. Make a decision, embrace it fully and then relax and try to keep confident, even though there are many ups and downs on the journey.

Second Opinion



In November, we found a cheap airfare to Melbourne and so decided to have a bit of a holiday. It had been a fairly full and stressful few months. Shortly before, I had read Ian Gawler's book *You Can Beat Cancer* and realised that there was a cancer centre near Melbourne associated with his foundation. I faxed and found out details, hoping to make contact.

As usual, we went with no accommodation booked but found a pleasant, well-appointed motel between Windsor and St. Kilda. We didn't realise it at the time, but as we had booked it at the airport, we got a much cheaper rate than if we had booked in advance. Melbourne was such a change from Auckland, with the wonderful public transport. We just loved the trams, with their distinctive sound, and you can get anywhere so easily. The city was alive and vibrant late on our first night when we took the tram to Prahran to find a supermarket. We had taken a motel room so that we could make the right food for me as I was trying to keep up my restricted diet. I managed to do my Qi Gong exercises every day, too.

After a few phone calls, we managed to get in touch with the Gawler Foundation and found their premises. It turned out that they were having their weekly workshop the next day and I was invited. This was an interesting experience for me. There were about 20 people, in all stages of cancer. Some of them were

obviously very sick. However, everyone was very positive, helping each other. There was a talk, guided meditation and visualisation and a time for people to have their say. I was disappointed not to have been able to be put in touch with something similar here in New Zealand.

We had a picnic lunch on the lawn, along with some others. There I met Liz who was a lovely young woman with a brain tumour. She was having lunch with her mother who had brought her as by now she was too sick to drive. We got talking and exchanged addresses. Later, we started communicating by email until her death less than a year later, leaving a husband and two young boys. She wrote to me how she thought I was very brave and that she wished she could try my way instead of the chemo which made her so ill. But she felt she had to do as she was told because of her boys. In the end, she suffered a lot and her final surgery left her blind as well.

This brought home to me how debilitating cancer can be and the speed at which it can kill, although I had had evidence of that shortly before I was diagnosed when my cousin died of pancreatic cancer within three weeks of going to the doctor. I had written to his widow about how hard it must be for him, lying in bed and looking out the window, getting glimpses of life passing by. Little did I realise that I would be in the same situation within such a short time.

We also made contact with the Royal Women's Hospital to try and see a consultant there for a second opinion. They were extremely helpful. We had brought fresh slices off the block of my cone biopsy. We had had a long discussion at the local Auckland laboratory about my smears before we left for Australia and it transpired that they had done an internal report on the review they had done of my slides, as they do whenever someone develops cancer. When I asked for a copy of this, I was told I could not have it for medico-legal reasons. This infuriated

me. It was my body. They were my smears. I had paid to have them taken, although I had not paid to have them read. It seemed they belonged to the laboratory or the government and I had no rights to bits of my body. The opinion was that it didn't seem to matter as I had now been diagnosed and would be treated. Nobody seemed willing to help me in any other way. It also raised the question of whether this report had showed anything about earlier slides on a reread. Surely I had a right to know. To me, this was vital information as it could give me some indication of how fast this cancer had grown, whether there had been signs of it in the past few years.

We had then written that *we required all the samples, i.e. smears, punch biopsy, cone slides and the remaining cone section to be made available. We are travelling to Australia next Wednesday, 8th November and we intend to take the samples with us. Are you going to assist us in obtaining these samples or are you another doctor whose first duty is to colleagues rather than patients? We require these samples to be made available to us no later than Tuesday, 7th November.* Only the cone sections were made available.

However, when we went for our appointment with the surgeon at Royal Women's, the pathologists had set up a projector and there was my anatomy in glorious technicolour on the screen. The surgeon was extremely helpful and spent quite a time explaining about the slides. Although he was called away to an obstetric emergency in the middle of our meeting, we were offered tea and all the staff were so considerate until his eventual return. He actually offered to operate on me in Australia at minimal cost. He was genuinely concerned. I really wasn't sure but felt it would be safer than in New Zealand, if less convenient and more expensive.

It was an excellent experience except, again, for the pathologists. They came in while he was away and took down

the screen and removed my slides, saying he had had enough time. The next day when we wasted half a day going to the hospital to get them back, they were extremely uncooperative and would not bring them up, even though the surgeon had asked that they do. It took the Staff Nurse phoning them and threatening to get the surgeon out of the theatre before they miraculously appeared. I am not sure if it was closing ranks with their NZ counterparts.

During the long wait in the ward, and with the stress of this lack of cooperation yet again from the pathologists, I became quite unwell. They were good enough to let me lie down in one of the side rooms, even though it was an extremely busy surgery day. All the women were being brought back from theatre with various bits missing - vulva, cervix, uterus, ovaries..... They all looked pretty sick.

I must admit, in spite of this, I was quite tempted to return in a couple of weeks for the operation. I felt much safer there than at National Women's where I had observed theatre orderlies wandering down to the café in their theatre overshoes. I had wondered at the hygiene. It all seemed so clean and efficient in Royal Women's in Melbourne. I was not decided though. It was a hell of a decision to make. I would have had to recuperate in the family accommodation across the road from the hospital as it was too expensive to stay on the ward. Still, it was a very generous and genuine offer. I later wrote and thanked him, after I had got back a clear report from my consultant. Naturally, the Melbourne surgeon was pleased for me, but did point out that smears are not a very accurate way of monitoring cervical cancer. *Al*t is your life I am concerned about. Somehow, though, I did not feel the pressure from him to conform.

Maybe things would be better now if I had had that surgery. Maybe they wouldn't. Only God can tell. It seemed a reasonable option though I was led not to take it. That is the

trouble with any decision. You cannot tell what would have been the outcome of the other alternative. One thing that did strike me, however, was that they seemed more honest in Australia in their assessment of side effects. When I asked about swelling of the legs as a result of removing the lymph nodes, he did admit that most of their ladies had some sort of problem with this. In Auckland, they breezily said that it was generally not a problem. So who to believe?

We found the Anglican cathedral right in the centre of town. It became a handy meeting place if we were separated. And there was a McDonalds right across the road where, if you went upstairs, you had an excellent view of all the comings and goings of the trams. I sat there with my glass of water and did a couple of sketches of the cathedral towers.

It was in this cathedral that we met an amicable chaplain who happened to be on duty to show visitors round on the day we first ventured in. He worked most of his time in a hospital with the dying. However, he was kind enough to come to our motel and counsel me as I was very troubled as to which course I should take. It was good to talk to someone totally detached, but who understood my situation and could relate to God. His knowledge of Anglican church history was formidable.

All in all, this stay in Melbourne was a much needed interlude. It was complicated by my very strict diet so I was unable to indulge. But maybe that was a good thing. I tried to stick to it and to make sure I did all my exercises every day. I had had an opportunity to see a cancer support group in action, I had got a second opinion, which, although it agreed with the first opinion, was communicated so gently, with real concern, and was certainly not pushy in the slightest. And finally, I had found some help with my spiritual needs. The visit was also full of amazing coincidences - but that is another story.

My Cancer Journey

Now it was decision time - and back to New Zealand with determination to overcome this hurdle in my life and to try to understand what was the purpose behind it.

Signs and Coincidences



We returned refreshed from Melbourne. I had loved it. However, I had to continue my efforts at beating this cancer. There were regular Qi Gong massage treatments and I had developed a good relationship with my new GP, Ric. This was a relief to me as it was vitally important to me to be able to have some guidance and someone to talk to about my concerns. I was reasonably confident - but scared as well.

Then there was the first colposcopy after my diagnosis. I was pretty nervous and terrified of what it might show. However, I was pleased to see that it is projected onto a computer screen so I could see. It was interesting to see a magnified cervix and get some idea of its shape so I could compare it with what I could feel. Brian took quite a few photos which was helpful to me. The consultant held the instrument steady so he could get a good shot.

I sent off an email to Liz for Christmas with my good news, hoping hers would be better.

24th December 2000

Dear Liz

I had hoped to get this away earlier to wish you and your family a wonderful Christmas and a New Year of health and happiness. As usual, things caught up with me.

I hope your new regime of chemotherapy is not too arduous. Does it give you any nasty side effects? You've probably been through the full range before. Poor you! Anyway, I do hope it does the trick this time. I shall be thinking of you.

I have had good news for Christmas. I went for a colposcopy 10 days ago and the gynae was surprised to find that all looked pretty normal. However, there were a couple of areas he wasn't completely happy about and so he did biopsies. Brian took photos of the TV screen where I was displayed in glorious colour. However, they are very interesting and useful for me to concentrate my visualisation. Anyway, I stressed horribly for a week and went back on Thursday for the results. All Clear!! At least, they think it is. A smear came back clear and one biopsy they reckoned was just new skin and the other was '>undiagnosable' which was explained as being unable to find anything wrong. They certainly couldn't find cancer!

So, my mixed regime seems to have paid off. Each of the practitioners would like to claim it as their own success. However, I think it is the combination of all approaches and I was led to the right people at the right time - first to the people for the supplements as I had dealt with them before but they put me onto the chap who could help with the herbal treatments and the strict diet (which I must admit I have slacked on rather too much over this pre-Christmas period). Then I met the Chinese doctors and I have found the Qi-Gong massage a tremendous help and the wonderful thing is that it has eased other long-standing problems so that I am becoming more

supple and pain-free. I have also lost 11 kg which I am really pleased about. I have also had a lot of help from Spiritualist and Christian friends who have tried, in their own ways, to find healing for me.

However, I know that it is my own deep (and unorthodox) faith which has allowed all these things to work. I know that if God had chosen this way for me to go, then nothing would have helped. And ultimately, I believe it is His choosing - or should be. However, it seems I was given enough warning to enable me to change my life around. We noticed all the signs which said I would be worse off, perhaps even dead, if I had radical treatment, although it may well be best for some people. And it has taken all my strength to go against the medical profession as their persuasion is pretty strong. However, we have been led by signs in our lives for the past 14 years so why stop now, especially when it was such a crucial matter of life and death?

I am really pleased at the results, although I am not slacking for a good bit yet (except diet over Christmas). I am quite aware that cancer could still be lurking there, and in fact, I got a lovely E-mail from Michael Quinn at Royal Women's in Melbourne pointing this out to me yet again. I know that and I know that he has to warn me. And I am vigilant and hardly trusting of the results. We'll see in another 3 months!

Anyway, sorry to go prattling on about this so much. But as you can understand, I am quite relieved. Would that you get such good news early in the New Year or when your chemo course ends. That would be wonderful for you and your family. It must

be a terrible strain on you all. However, as you say, it is those you love who keep you going as you feel you have to keep on for them.

Windy and wet in Auckland today and probably for Christmas. Shame. Rules out Christmas on the beach. Still, we are doing nothing much except for trying to sort out the chaos in our house and garden as everything has been abandoned for the last 4 months and we are drowning in stuff. Brian hopes to get our first book out in February - but that means his typist (i.e. Me) has to work harder. I don't know! Still, it will make us both feel better to be getting on with things again.

This lot of kittens has been a trial. They were fine and bouncy when we got back from Melbourne but shortly afterwards we got cat flu through the lot of them. We have acquired/are feeding several strays at the moment. Anyway, I nursed them for over a week, wiping eyes and noses with colloidal silver several times a day. But the virus was just too much for them and one of the mothers was very sick and couldn't look after them much so her mother (the mother of 4 out of 7) took over. I eventually put them all in a box together and took them to the vet - over \$100!! Brian nearly had a fit but I couldn't just leave them getting weaker and weaker as I had been nursing them all myself.

One eventually died. She just wouldn't eat at all and I couldn't persuade her and even the medicine made no difference. She died just an hour before I had to go and get my results so we buried her before we went right beside her great grandmother (who was born in Scotland and was the only one of our 4

cats we brought with us when we came to NZ in 1995). The others are all now full of bounce but were not well enough to go to new homes before Christmas and so I have a problem. Oh well! I enjoy them. Though I am always in trouble with my 26 year old daughter who runs a cattery and now is full with 54 cats over the holiday period. She keeps telling me off for letting them have kittens.

Actually, Sooty, the one we brought from England is interesting. In 1997 she went missing for a couple of days and I was just going out to put notices in letterboxes about her when I noticed she had struggled home and was in a terrible state, bleeding vaginally and dehydrated. We took her to the emergency vet who rehydrated her clumsily and gave her antibiotics. She said she had dead kittens inside her and needed a hysterectomy. We said she was too weak and that it would probably kill her and that anyway, she had come home and that was where she would stay, not in some clinical cage in a strange place. The vet was not pleased as they would lose a lucrative out-of-hours operation.

That was on 6th September, the day of Princess Diana's funeral. My friend Mary came round to watch it on TV with us as she didn't want to be alone. She brought some Bach flowers and homeopathic remedies for Sooty. In the middle of Diana's brother's speech, poor Sooty stood up and peed floods all over the carpet. She was bothered as she knew it was wrong. But she couldn't help it as she was too weak to go anywhere and she had had loads of fluid put into her. Next day she had improved and we took her back for more antibiotics and fluid. This vet was

more competent. Sooty picked up quickly after that, starting to eat bits of chicken, etc and drinking by herself. We didn't take her back any more.

But then we got a visit from the SPCA saying we were maltreating a heavily pregnant cat. We were livid. It was the vets who had done that. Sooty heard the rumpus on the porch as Brian nearly marched the guy off our property. We had done everything we could for her and no kittens had been expelled so the vet was wrong. I think she had had a miscarriage and got an infection, which was treated, but that was all. Anyway, Sooty got up, casually walked out onto the deck past the officer, jumped down and went to pee under a tree then came back inside. Brian said "There's your heavily pregnant cat!" It was really distressing as it was so unjust - just because we chose to treat her our way which didn't involve heavy vet's bills but was much kinder to the animal.

Anyway, the upshot was that Sooty lived until this year - a full quarter of her life more. She went on to have more kittens and then seemed to enter a natural menopause. Then again she didn't come home one night and the next day we found her in her box on the back deck with all the fur stripped off one back leg from hip to claws. I don't know how she managed to drag herself up there. We don't know if it was a dog or a car. Anyway, I nursed her for a day as I didn't want to go back to that emergency vet. The next day we took her to our vet and decided to have her put out of her misery.

The day after that my cousin died of pancreatic cancer after only 3 weeks since diagnosis - a huge shock. A week after that, I started my new job and a

week after that got my own diagnosis from a colposcopy and was told I must have a cone biopsy. What a month! I delayed for a couple of weeks on the cone as I wasn't happy but eventually had it done, strangely on the day nearest to Princess Diana's death - 30th August.

And the day I got my results, the day they told me I had incompletely excised invasive cancer, was 6th September, three years to the day from her funeral! I only realised it when driving back from work a few days later when I suddenly thought of Sooty as I came out of a road opposite the cemetery. I remembered we had been told she would die if she didn't have a hysterectomy - the same as me. But she had been fine and in the end went from something totally unrelated. And I took strength from that and knew I had made the right decision.

You may think it a bit strange that I go into this at some length. However, Brian and I got strong signs about Princess Diana's death several weeks before it happened, though we were one day out - calculating it as 1st September. Brian even wrote to Al Fayed a couple of weeks before advising him to cancel the sale of the Duke of Windsor's belongings - a sale only made necessary as Dodi and Diana were going to live in his house in Paris and needed it cleared out. But it is such strong signs all the time in our lives that help us to make decisions, especially difficult ones.

It might seem odd that I put such store in what many would just dismiss as coincidence. But hundreds of things have happened to us over the past 15 years, each one of which so-called rational people prefer to dismiss as chance. It makes them

feel safer. To us, they are all part of a very coherent pattern which is far from chance. It's all evidence for the existence of God. And, in fact, Brian has changed the title of his book recently to 'Enigmas of God' and he describes how, as a conventional, rational scientist, he was forced to look at Spiritualism when strange things happened at the time of the breakup of his marriage and then lots of coincidences such as meeting me and both of us already linking to Egypt in different ways.

Interestingly, a few years back when he had taken a wrong turn in a strange town, Brian came across a notice outside a church saying 'Coincidence is God's way of remaining anonymous'.= Very apt, in our experience. A further twist occurred in this last July (that same month I described to you above), that same church was burned to the ground. It was arson but that seems symbolic because the modern church has been destroyed by the hand of man. It has no connection to the faith that inspired the builders of the cathedrals or the writers of the Book of Common Prayer.

Sometimes we feel really overwhelmed at the depth of so many strange connections in space and time and it is this, as much as anything else, that has given me the faith to adopt the path I have when faced with what the medical profession tells me is my near certainty of dying from cervical cancer. To me, they seem more like priests pursuing their own religion but, in the end, their religion fails with the body. They can do no more to help you when the heart stops, when the pump which is all they consider it, no longer pumps.

But our signs and pointers give us a faith that there is something beyond space and time, that there can be life after death, but there is a judgement, there is a right and a wrong in all things, and that's not what people want to hear in this world.

My cancer has, I suppose, caused me to face the prospect of my more imminent death and it has certainly taught me a very great deal about so many friends and relatives. It's clear to me they cannot cope with death and they have either tried to put pressure on me to have a radical hysterectomy, do as I am told, or they have ignored me altogether, just when I needed encouragement and support. Those are the only ways they have to cope with death - rely on the doctors who give life of a sort, or pretend it's not happening.

So, it's been a real eye-opener and I have been very hurt by many people. But I do believe there's a purpose in everything. I am trying to make the best of things as they are. I don't really know what the true situation is. I'm not convinced that the cancer is completely cleared. But I do believe that I have taken the right path. I trust in what, in my experience, is the most trustworthy source of advice. I think each of us can be led if we choose to look and listen. The trouble is that in the modern world, if you don't take the conventional approach, it is very hard to get any support at all.

Anyway, I hope this isn't all too deep a sermon for Christmas. Maybe 2001 will be a new odyssey of understanding for us all.

Hope you all have a wonderful Christmas. Do keep in touch and let me know how your treatment

My Cancer Journey

is going. I'd be really interested to hear. And if I can help you with any alternative ideas, then let me know. I am thinking of you and trust that you, too, can find true healing.

Best wishes to you all,
Jenny and Brian

Guidance



We continued to correspond and I found it a heartwarming experience. Poor Liz continued to have relapses and had to endure more treatments: She expressed a wish that she could have taken my approach as she hated the treatments and didn't feel they were what she needed. However, as a young mother, she felt pressured to do what the doctors said, even though she didn't have faith in them. I tried to explain to her my reasons for choosing as I did, in my circumstances.

7/5/01

Dearest Liz

I was so saddened to get your latest e-mail - didn't get it until yesterday when I was on the way out for my Chinese Qi Gong treatment. Brian hadn't checked the emails for a few days and when he found it on Friday night, I was sound asleep with exhaustion from overwork and a pretty torrid emotional fortnight at the worst time possible for my work. My ex-mother-in-law died on the same day that Brian found out he was going to lose his main job and therefore income. My ex came back from Russia and I was talking with him for the first time in 15 years. Still, all minor stuff compared with your news.

What can I say? You must be pretty upset and fed up with it all, especially after trying so hard with your chemo, etc. However, you are pretty tenacious and strong. How does it all affect you? Are you in any pain? Or is it just inconvenience and, of course, the worry?

You ask if I have any answers. The only thing I can think of in the way of medication is the Co-enzyme Q10 and coconut oil I told you about in my last E-mail. I take that regularly now and if things got worse, I would take it in large doses. I heard about it from my GP who is very open to these things and subscribes to some reputable journals which look into alternatives. The compounding laboratory I told you about is now doing some research on it here in NZ. I also take large doses of Vitamin C throughout the day, especially now in this time of stress.

I can really only explain to you my reasons for choosing the course I did. And it has been tough flying in the face of the medical opposition and I could not have done that without Brian's complete and unwavering support and without my deep faith. You said to me once that you felt my way would be better than trying all the medical approaches but that you felt you couldn't because of your worries for your family. You need to look at what you honestly feel in your heart is best for YOU and not for anyone else. It is easy to be swayed by what is best for others - doctors, family, etc. and what makes them feel safer.

I felt that if I took the surgical approach, I would not survive it. They kept telling me I was unlucky all the way through. And when they told me I had a 90%

chance, I reckoned the odds were not good enough. I knew in my heart I would be in the unlucky 10%. I had been to date, anyway. Brian forced the surgeon to admit there was no way for him to tell who would be in the unlucky 10%. And I knew I could not accept radiation. They just did not seem sure enough themselves and I could not trust them. The radiologist was actually quite deceitful. The surgeon pulled him up with a sharp AShe means permanent damage@ when I was trying to ask about likely outcomes. So that left me with the option of getting my own body as strong as possible and trusting in God.

We are not conventional Christians by any means. As far as I know, there is nobody else who has our beliefs entirely but our way of living and trusting has come about with 15 years of experience and research. We have followed signs and coincidences and found that you can trust them to guide you.

We believe in life after death - not physical resurrection but that the spirit survives and, if judged good enough, goes on to >heaven= although nobody can really know what that is like. We act as mediums quite often (though not on demand) and receive communications from good people who have died. Brian is working on his book trying to summarise 17 years of evidence. It is called The Enigma Variations. There were so many strange coincidences even with the title and the cover design. That was all in March-May 2000, before my cancer came to light in August.

We use coincidence as an indication that the

messages from the dead are what they purport to be. If there is no evidence in the physical world linking to that message, then we are wary. As an indication of accuracy, we were given the coordinates of the Lockerbie plane crash 19 days before it happened, given which plane would crash where, and why. It was in the form of a code. We only cracked the code after the crash. And we lived only 40 miles away. Brian also worked out on the night of 16-17th August 1997 that Princess Diana would be murdered. The coincidences gave 1st September 1997 as the date - only one day out, and that was because Brian took the wrong time zone. He had even written to Mohammed al Fayed on 15th August, warning him that his son would die if he failed to heed the warning.

I tell you this to explain why I chose as I did, not to try and preach in any way. I tell you just so you can see why we have come to trust signs and coincidences. We see them as somehow being a kind of guidance from God that we can trust. However, it may help you in your decision.

I have much left to do in the world, helping Brian to get his books out. Once we have done that, our work will be finished and I would be happy to go. I felt very strongly that I would have serious problems with any medical treatment of my cancer and that I would be no use to him for quite a long time, if ever, because of it. At least I was relatively well and likely to remain so for some years, even if I didn't manage to get rid of the cancer. That would mean that I would hopefully be able to do what I needed in the time available. Surgery seemed to me to be so final

and would destroy that option. I was told again and again that it was the only option, and that it was a relatively simple procedure, although a major operation, and that it would take a while to recover.

I came to distrust the doctors, each of whom was pushing their thing and covering his own back. You see, if you do everything that they say and then fail (i.e. still die), then they can say that they have done their best and it was very sad, etc, etc. However, if you follow what you believe is the right way and it goes against their (rather limited) advice, then they would say you are a fool. But nobody at all can tell what the outcome of either course will be. They can give statistics - but of what real worth are they? Even if there is a 1% chance of failure and that you are that one, it is not much comfort.

The doctors try, admittedly, but they are very narrow in their outlook and the competence of different doctors and surgeons varies enormously. Each concentrates only on his area of expertise. The gynaecologist, for instance, sticks to the womb and forgets the rest of the body. In spite of my miraculous (according to my GP) healing, my gynaecologist never asks what I am doing as it may possibly help others. For the rest, there is still only the knife or radiation. Other doctors I have seen in this, such as my old gynae and my old GP just don't even respond.

I believe that the purpose of this life here is to test us. I believe that God will take me when He is ready and that it is my duty to keep as strong as I can in the meantime. I believe that if I truly trust and try to do as I am guided, then God will look after me. That may not necessarily mean keeping me alive, no

matter how much I want it. God has His own purposes and it is not for me to question. This probably sounds to you pretty fundamentalist stuff. However, we have come to these beliefs over 15 years of struggle and research and gradually understanding. And my faith sustains me now in my chosen course of action.

I don't know what you believe and I would not try to push my faith onto you. However, I set this out so you can see the background to my choice and to try and maybe help you with your decision - but it must be YOUR decision.

As an example, I will tell you the following story. We went to the chapel at the top of National Women's Hospital and we found that the big picture windows looked out over One Tree Hill and its obelisk. This is a landmark in Auckland, except that from October last year, it is 'No Tree Hill' as the tree had to be chopped down. That was the day we decided to come to Melbourne - just after we had been to see the tree for the last time - 20 days after we had looked across to it from the chapel. That day in the chapel was the exact anniversary of our arrival in NZ 6 years before, a time which has been particularly unhappy for us. My parents had driven us up there straight from the airport.

I decided then in the chapel that perhaps I should have the surgery and we could look on it as a new start. I wrote in the Visitor's Book *Al will lift up mine eyes unto the hills from whence cometh my help.* @ I tried to tell myself it was the most rational decision and Brian was actually very, very relieved. However, all the way home, I felt utterly dead. I said

when we got home that I would face the operation and it all seemed OK. I felt better for having made the decision.

Then, as I looked at a book in the evening, suddenly I became so distraught and screamed and thrashed around and eventually collapsed into a deep sleep. When I awoke the next morning, my decision was made. I was not having surgery. I was trusting in God and in the help I knew I would find. Brian would give me healing as he had done in the past and I would just trust and see what happened. I felt calm and happy, and that day I went out and dug a vegetable garden to grow fresh things. And, apart from a few fears, especially at the moment because I am unable to get the rest and lack of stress I need, I have remained confident and my health has improved to be better than I can ever remember.

But, for a while there, Brian had worries and wondered if we should go the medical way. However, my body told me in no uncertain terms what path I should take. Brian had felt maybe it was safer and his caring for me made him feel that. Also, he knew that I would take the course he suggested and so he was glad that I had had such a strong reaction to show that it was truly ME who was making the decision and I wasn't just following what he thought was best. After all, it was my life, and my possible death.

Then whenever we went back to National Women's to see surgeons, psychologist, counsellors, etc, etc, there were coincidences that said "Do not have surgery!" These helped me because everyone I spoke to at National Women's advised surgery. I was

even told I would die if I did not have it by one doctor - which made me really angry. How dare he!

So, it is for each person to choose their own path in any circumstances. But we are always given signs and guidance, if we know how to look. I wonder at your comment that you dislike the >horrid= surgeon who operated last time. If you do not have confidence and a good feel about someone who is to have such a critical part in your well-being, then that is not a good sign. Perhaps you should look at why you find him horrid. Is it something deep in you warning you?

Perhaps you met us for a reason? I don't know. We have a totally different outlook on things from most people and an unshakable faith in the way we are guided and helped. We only met you because you and your mother had lunch on that bit of lawn and I had a brief lunch before going on to Royal Women's for my appointment. I met nobody else from that group really. The Foundation didn't even bother to send me the contacts in NZ they promised. I didn't like them much at all. I had admiration for the members of the group and their struggles and wish I could have done more. But time intervened.

However, things slotted in pretty well during our short stay in Melbourne. We only decided to go on the spur of the moment a week before, because of more signs and coincidences, in part to do with my dead brother and the chopping down of the tree on One Tree Hill. Brian was going to go to the travel agent but I met him by chance so we both went. I was supposed to be on my way to work. We found it was the last 15 minutes to closing time on the last

day of a cut price offer which had been going for a couple of weeks. So, it all fitted!

If things are right, they seem to all fit together. To go back to my story again, I will tell you something else which may help you. After getting the news of my invasive cancer, I went to my GP who was adamant that I should have a hysterectomy as soon as possible. I told him, yet again, that I felt it was the wrong decision for me. His reaction was to virtually cut me off. He said he could no longer treat me. I was ignoring his advice. At least that was honest, but I was devastated because I needed support and continuity then more than ever before. Just before we had gone over there, I had phoned the laboratory I told you of as the director there had helped me in the couple of weeks before my cone biopsy. I had had a lot of help from them over hormone problems and I got my natural progesterone cream from them.

When I got home from the GP, there was no message on the answerphone and so I felt really sad and alone. However, I hadn't been in the house more than a minute or so when the phone rang. It was the director's secretary. She said she had heard my message and just had to phone me back straight away. They had a new South African chap who had just started working with them and I should be able to get an appointment on the Saturday. So, as one door closed, another opened.

Brett helped me to have confidence. He put me on a strict alkalisation diet - vegetables and rice at first, then gradually adding things. He also put me on a strong herbal mix, some homeopathics to support my liver and lots of supplements. Apparently he has

had good results with quite a lot of serious and quite advanced cancers. He, too, would have been happier if I had had a hysterectomy, but I suspect that was only to cover himself. He is unable to advise me not to have as it would not have been ethical and he accepted my decision quite readily. I lost 12 kg which was great as I was carrying far too much weight and my general vitality soared. I asked him for some other contacts from his other patients and phoned them.

One woman, who had had breast cancer, had surgery once and radiation treatment. She told me that when it came to her second lot of radiation, she just got off the table and left the room before they could zap her and she refused to have any more. She is fine now. She told me she just felt suddenly it was wrong. (It is funny. I have the same feeling. Every time I think of surgery, I get as far as going into the theatre and then I feel myself ripping the IV out of my hand or arm. It is the same with radiotherapy. I feel myself ripping the radiation rods out of my inside.) Anyway, her father was being treated by Brett for a serious form of bile duct cancer and he was doing really well and out mowing the lawn.

They put me onto a new GP they also use, on the other side of Auckland, admittedly. He has been great and provided the support I needed. Also he comes up with new ideas for me to try, rather than just tolerating my stupidity. He is supporting several cancer patients who are doing well. He, too, did suggest I had a less radical surgery, and is a bit mystified at why I am so well. He keeps saying "Perhaps the gods are smiling on you."

He is closer than he knows. I am sure it is God, both directly and indirectly. By following guidance, I am led to the right people.

Shortly after finding that GP, we went to a Mystics and Natural Health fair in our local town. It was not particularly good and we came home. However, Brian said "I am sure there is someone there we are meant to meet." We did not know if it was to do with our books or not. He felt we should go back. He felt that maybe it was the Chinese people in the corner, one of whom had spoken to him in the morning. We went back half an hour before it finished. I suggested Brian have a treatment to see what he felt about it as I trust his judgement in these things and I knew he would get what was right. The chap was pretty accurate and so we arranged for Brian to go for another treatment at their clinic.

While there, I spoke to the director, Colleen, who is a Chinese gynaecologist who is unable to practise here as NZ professionals are so terrible to foreign professionals in NZ. She had almost completed her midwifery retraining to practise that here. I asked her if Dr. Chen could perhaps help me. He checked me out, gave me a treatment, and, within a few sessions and following his exercises, I felt so much better. I had a smear test a couple of weeks later and the result was clear.

Now, I don't know if it was his treatment, or Brett's, or the colour therapy I was led to develop myself, or the colour therapy advised by a Spiritualist friend which had been developed by someone whose wife had been very ill..... All I know is that I had healing from Brian on a regular basis throughout. He has

given me healing in the past and it is very, very powerful. I could feel the warmth and the changes. I have utter faith in it. And it comes from God, I know. I had a friend who insisted that it was wrong if it didn't come Athrough Jesus@. I do not feel that is necessary. I have often given healing and it does come direct.

So, in conjunction with Brian's healing, I was carrying out all these other things which I had been led to by following where we were guided. This is the way we lead our lives, and have done for the 15 years we have been together. It is not easy. But we have survived against all odds. And the combination of things meant I was able to grow stronger and change my life around. It has also made me think about a lot of issues.

One little illustration about the multiple approach. We had to tow our car to have it fixed. It had broken down just when I was about to go onto the motorway on the way home from work on a rainy night. As luck would have it, it was 2 minutes walk from the only phone in a 20 km journey - right by a Service area. I could phone Brian, get some chips to eat and be safe until he came. The AA towed us home as it was the cam belt which had gone.

Anyway, when we tried to tow the car round to the garage with our other car the next day, the tow rope broke twice. Brian realised that he hadn't used enough strands and doubled it round. Then Brian said how silly of him not to double the rope at first. Then suddenly we realised we were being given a strong message. We were not to rely on just one strand. This indicated to us that with using different

strands of treatment for strength, it would be OK. I don't know if you can understand this thinking - it is very briefly put but follows on from our whole philosophy. The problems with the innards of the car were also relevant too.

I have been sending you healing since I got your e-mail. I hope you don't mind. I was thinking of you and found my right hand was burning hot. I was aware of it separating out and shrinking your tumour which I could clearly visualise. I was aware of a vision of you in the fleeting time on the lawn and in the car and also of looking up your address on the map of Melbourne, seeing the map sort of superimposed. I know that probably sounds silly but it was as if I was getting a correlation of you and where you are. I lay in my Chinese treatment and felt some of it going to you. I did ask them if they knew of anybody in Melbourne who was skilled in this type of Qi Gong but they didn't.

Anyway, it continued into the afternoon and evening, whenever I was quiet. I had to go down to work with Brian and I was desperately tired and slept in the car while he looked at the ponds and changed the pump speeds and while he was testing the effluent in his laboratory. I then came into the lab, sat back in a big chair and went into a meditative state and it was you there, rather than me. I had been told by Dr. Chen I should do some of my exercises again, but it seemed to be directed more to you.

One thing you can do which I found very helpful is to meditate. I didn't like the thought of meditation and still don't like the sort of guided meditation they

did at the Foundation at Malvern. However, I was advised by Dr. Chen to sit at the front of a chair with my feet slightly apart, sitting erect but relaxed and to put my hands loosely over my cervix area - and for you it would be over your tumour which I feel is low at the back of your head. Then just concentrate on your hands and on the hurt part of your brain.

Think about gradually clearing the tumour out. My chiropractor said to think of putting it somewhere, say in a part of the garden. It does work. I could feel myself clearing out my whole cervix and working on the lymph glands, and gradually I became confident that it was all cleared. You could relax and feel your hands moving over your head, down your neck and spine and gradually clearing it all out down to your feet. I find this is especially helpful when I am under stress and it helps to relax all the neck and the back of the head and allow a proper energy flow. It is all so difficult to put briefly and it is easier if I could show you.

I wish so much that you could come over here or that we could go there to help you. Brian can help people if they have the right attitude, and I trust his healing totally. We have one spare bedroom which we could clear out here if you feel you can come over here.

I hope you haven't found this too tedious or too much of a sermon. It is extremely difficult to know what to say so I thought I would just be honest and lay out what I have found helpful and why. Then you at least can see the validity of a different approach.

It has to be YOUR decision - not your family's, not the doctors', not society's - but YOURS. It is your

life and one of the wonderful things about cancer is that it shows you that very clearly, if you let it.

I have found it very liberating. For the first time in my life, I was able to stand up and say ALet me decide. This is one decision I must make that I feel sure of. I had always taken the easy course and been pushed around a bit, gone with what my parents wanted, etc, etc. This has given me an enormous strength. I don't know what the outcome will be of my illness. It seems to be OK at the moment but I am genuinely worried about the stress I have been under and its effect. I don't seem to have much choice on that though.

However, whatever the outcome, I know in my heart I made the right decision. I cannot know what would have been the outcome of the other choices I had. But I am happy with the choice I did make. And you must be happy with the choice YOU make.

Whatever happens, Liz, you will have gained strength and understanding through the experience. I pray that you reach a decision that gives you peace and confidence. Life is a struggle and a learning process and is not meant to be easy. I think that those who have to face all the questions you do when struggling with cancer are fortunate in many ways. They have more of an opportunity than most to clarify their thinking and to change. Please keep in touch and let me know what you decide. You are most welcome to come over for a bit if you wish and I could get you some treatments with Dr. Chen and Brian could give you healing. In the meantime, I will continue to send you healing (not in the Spiritualist way but just because every time I think of you, the

healing just seems to flow). If you want to talk any of this over, feel free to phone.

I hope some of this has been helpful. It is not meant to preach. It is not meant to try and persuade. It is meant to help you to clarify what really is best and to show you the way I have lived my life and so carried on the same philosophy into fighting cancer. It is to show you how coincidences can help you make decisions. I hope it has not all been too heavy for you, especially at such a time of worry and stress as you make your decision. Do think about it as I really do care what happens.

Relax and let your mind float gently over the options - and remember that one of them is to not take a medical approach at all but to trust while taking strong measures to strengthen and cleanse your whole system, to give yourself a fair go. You will not be given this option by the doctors. What is more, they will over-estimate the likelihood of success and play down the disadvantages of their treatments. The extent of their honesty varies dramatically from doctor to doctor and it is difficult to assess unless you pay close attention to the little signs. Never under-estimate your gut feeling.

Nevertheless, not having further conventional medical treatment is still a valid option if you take it for the right reasons. Touch each of the options with your mind and see what you feel deep down. Don't think about the fear which will naturally be there. Think about what feels right to you, for you. Think about any signs you notice and the way things link together. You will feel at peace with the right choice for you. You will probably still be scared. You

Jenny Cocksey

wouldn't be normal if you weren't. It is the unknown, after all. However, trust, accept and have the strength and the courage. Each of us has a destiny. I trust you will find yours.

Find peace, Liz. Find peace in your decision. Whatever is right for you is what counts. But you will need support in whatever choice you make. Unfortunately the doctors only give support in their way if you follow their way, so if you make the choice of seeing what God really wants of you, you will have to rely on the support of family who truly want the best for YOU and on your own inner strength - and God will help you. It is a hard road, but worthwhile.

Please do keep in touch. My love and strength to you. Keep smiling. Keep courageous. Relax and see what comes to you to help you in your decision.

Lots of love,
Jenny

PS: I have felt exhausted and weepy for the past couple of weeks, mainly because of the funeral and over-work. However, since starting this letter to you several hours ago, I have felt quite buoyant and alert. It is amazing what thinking about someone else can do. I hope I haven't tired you with it. It is difficult to distil the wisdom gleaned over 16 years into a few paragraphs. And I don't want to sound as if I am telling you what to do. I am trying to just show you how I have gone about the decision process - and it is a difficult thing to have to decide. Courage!

I know I have mentioned many of these things before, but

they are set out here as I tried to help Liz. She was so brave and positive and I really felt for her. I enjoyed our correspondence with her tales of children and their antics. They must miss their mother. She finally decided to go ahead with surgery in Sydney but never really recovered. Liz finally let go of life on 27th September 2001 after a brave try to stick around for her children.

I continued to correspond with her husband for a bit and was pleased to be able to have a long phone conversation with him the next time we went to Melbourne. He told me how Liz had hung on and it was not until a nurse said in her hearing that she would be dead soon, that she finally gave up her struggle. I was privileged to have known her for that short time and hope I managed to help her in my own way.

The Fantail



I felt on course until I did the stupid thing of taking another part time accounting job. Mind you, I can see now why I had I as it linked in so strongly to our coincidence work, especially that surrounding the Twin Towers disaster. I loved it as it was at the local airport in a flight training school. But things turned sour when my predecessor wanted to come back to her old job. Anyway, I was under extreme stress. I was expected to do more work than the time allowed and learn the job at the same time. There were two people trying to use the computer and I could never get any uninterrupted time on it to get the accounts entered.

I was so worried about the stress I was under. I had ceased all my meditation as I just didn't have time and my intake of supplements was irregular, as were my meals. Then my ex-mother-in-law died which distressed me. My ex-husband came back for the funeral and there were family problems. Just after that, I heard that Liz had got much worse. The surgery had not been successful.

Looking back, I can see it was a mistake to take on another job. But I was pleased to feel that I could manage and the work was interesting, if stretching me a bit. With some cooperation, it could have been a lovely job, especially as my other one in the gym ceased within 6 months or so when the business was sold.

It is probably the point at which the cancer started to come back.

17th December 2001

Bad news. I got a letter from National Women's on Thursday saying there was a further abnormality. I saw my GP today and he confirmed that there is at least CIS Carcinoma in situ (i.e. where the cancer hasn't yet started to break through the bottom layer of the skin) and most probably invasive carcinoma. What really angers me is that that biopsy was taken on 30th October and the results were not sent to the specialist until 12th December!! - That is a full 6 weeks!

Where was the sample all that time? And especially as it showed cancer! That is the laboratory for you.....! I am distressed, though, because I had suspected problems back in July as I was so stressed about another job and was sacked without any warning. They used my illness as an excuse which was illegal and I was angry that I had not been able to talk to my boss about the problems with the job as it was not working out.

I had worried that all this stress, and particularly the way it was handled, would make the cancer come back and my instincts were right. The consultant took a smear in August and it apparently came back showing ASCUS Abnormal squamous cells of uncertain significance, i.e. they are not sure. However, the different cells could just be from inflammation and nobody told me - just that it was fine, as apparently they do not even do a colposcopy

for that grade of smear. That is like a replay of last time. The only thing then was that at least the local laboratory asked for a retest 2 weeks later. The hospital laboratory just said another 12 months! If they had told me, I would have immediately asked for a thin prep smear back in August. As it is, I didn't find out until 30th October when he took the biopsy. And now another 6 weeks has gone by.

Anyway, I am still not going to have surgery. I just cannot trust them at all, especially after this latest fiasco! It is just one error or omission after another. But it is hellish news for Christmas.

The worst is that I had been lulled into a false sense of security, especially as a smear also taken on the 30th October had come back with the annotation that there was no evidence of carcinoma, merely changes consistent with inflammation/repair.

When I didn't get the results of the biopsy, I thought it was probably the same and then forgot about it. So it came as quite a shock. It wasn't only shock. It quickly turned to anger that I had been, yet again, put at risk by poor systems and follow up. I had not even been told of the ASCUS result which was really bad. I had no idea there was anything wrong.

Sorry to go on in detail, but you might find it useful in your fight against the medical establishment. Nothing has changed. Nor is it likely to with the present complacency.

I realise my mistake and only hope that it is not too late to rectify it, that this is just a shot across my bows. I had put more energy into being buffeted by others' needs than my own fight, especially as I had been led to believe that the stress hadn't

affected me before and that everything was OK.

Work leaves no time for me, especially as Brian has been ill for several months with an overactive thyroid which has left him tired, breathless, with pounding heart, anxiety, losing weight, etc. We have been trying to get to the bottom of that and wonder very strongly if it was not triggered by a course of triple therapy antibiotics for helicobacter which Brian reckons he didn't even suffer from anyway.

He is sure it was a false positive on the test. You know, these tests are all quite dangerous when they throw up false results. And the trouble is that the doctors take them as gospel, instead of looking at how the patient really is or feels. That is what caused my first problem and now my second, and probably what has caused Brian's ill health.

It has been very illuminating looking at the thyroid question. They automatically send most patients for a scintillogram which involves injecting a radioactive substance. Brian had decided not to have that when we had seen the specialist privately. However, his private appointment had taken so long to come through that an Auckland Hospital appointment had come for a few days later so he decided to take that one up too. We couldn't believe it that they routinely send everyone for this test. When Brian asked about it he was told that it would tell them if he was a candidate for radioactive treatment of the thyroid, rather than waiting to see if the patient responded to the medication first. What a scandalous waste of resources!

Enough on health! But I thought it might be of interest in your battles. Now my real one starts! - or is it continues?

But back to this cancer problem again. The surgeon decided he had to do something and said he wanted to do a radical cone, this time under a general anaesthetic. I was most concerned

about this as I don't take anaesthetics well. Also, as I had bled so heavily with just a small cone and he couldn't get all the cancer because of the bleeding, what would it be like with a much larger cone? If the bleeding was excessive, it would lead to an emergency hysterectomy, with a much greater risk of damage to bladder or bowel.

He said he would open a theatre just before Christmas. I was bothered but agreed to present myself in a few days, on 21st December. This just gave me time to clear up the wages and accounts from my job and hand over to Suzanne for a period. Trouble was, she took over completely and I lost the job because of it. Never mind!

I was nervous but decided it was for the best, whatever the outcome. Then came several strong signs against it.

Brian went to make a cup of tea and when I came into the kitchen, he was trying to chase out a fantail which had somehow got inside. To do that it had to fly through two doors and along a covered and enclosed deck. The fantail is the sweetest little bird which is not afraid of people, a little like the northern robin. It tweets and dances on twigs, spreading its magnificent tail out into a fan. Now the Maori have a saying that if a bird, and especially a fantail, comes into the house, then there will be a death. The last time it had happened, my ex-husband's mother died. I freaked and said that I just wasn't having surgery at all. I am sure that bird was sent by God to warn me.

The second sign was even more pointed. Often when we went over to the doctor's, we would pick up a sandwich and take it down onto Howick Beach, which was very relaxing. You can sit under the Pohutukawa trees and look right out over the Hauraki Gulf, across to Motuihe and Waiheke. Brian was taking some significant photographs there the previous year to do with the Lockerbie plane crash for which we were given signs in advance. Suddenly his good Pentax lens ceased working and,

no matter what he did, it still would not work.

Sad, he put it in a plastic container with the round red lid, wrote on the lid "DIED 21.12.00" and took it over to Pt. Chevalier to someone he uses to fix his cameras. This man wrote above this "COCKSEY". However, it could not be mended so it was stuck in a cupboard. For some reason, it appeared just after the fantail incident. I saw it and it looked for all the world like a tombstone, with my name and the date of the operation. No, I most certainly couldn't go ahead with this surgery.

I phoned my elder daughter in England. Her reaction was "Thank heavens, Mum. I was just about to phone you and say that, even if you were walking out the door, please cancel the operation. I am more worried about that than the cancer." I was interested and relieved to hear this. She has been known to be quite psychic when it comes to people turning up at the door and other things.

Then came the problem of cancelling the hospital. I must admit, I came under a fair bit of pressure to continue with the surgery, no matter what. But still I had the visions of pulling the IV out of my vein just before I could go unconscious. I tried to contact the surgeon to apologise but didn't manage to as his office had already closed for Christmas.

It didn't make for a very happy Christmas, though. Obviously the cancer had started to grow again and so I must take more and more care - if it is not already too late!

And at New Year, I had an inkling of what it might be to be in the last stages. I was helpless with vertigo, not even able to move my head or open my eyes without the whole world spinning, it made me wonder more about dying. The beautiful day that was New Year's Day, the best we have had for months, just continued without me being part of it. My whole being was concentrating on getting through what I had to. It was a strange and thought-provoking feeling. And I needed to know that if it

was for real, that I could say goodbye to those I cared about.

Yet I was alone and sick as Brian had had to go and check the works, and it was quite scary. I couldn't even get up for some more water.

I felt very bad about cancelling the surgery, especially as the surgeon was trying to act quickly to make up for the inordinate delay in getting the results back from the laboratory. However, the signs said NO!! I could not ignore them, not without denying my life and the way I had lived it for the past 15 years, using coincidence as a guide and pointer if I were in any doubt as to the best course. It was such a shock to find that things were actually worse again than I had thought. Though I do know that stress of any kind is the worst possible thing for me. Every time I have been stressed since, I have had a relapse of some kind. But how to stay calm and unfrazzled??

Be Gentle



I was a little afraid at going against what seemed the obvious way to go, that is, to have this further surgery. However, on the whole I was quite relaxed and was sure it was the right choice. My main worry was that I would now be totally rejected by the hospital system. Still, the decision was made and now I had to turn my thoughts and actions towards more relaxation and some stronger measures to overcome this thing which was threatening to engulf me.

The following experience just happened to me, unbidden, and was very therapeutic.

11.50 pm 27th December 2001 Thoughts in the Spa - Freeing Myself

I swam 500m in our pool in the dark and the rain, with thunder in the distance. Quite cold towards the end but feeling good with the effort. Got into the spa and relaxed completely. It is a bit like being in the womb again, I guess. It is almost dark, the water is up to my chin and I am floating free, though anchored to the bottom by my own weight unless I let go. There is the steady sound of the pump under the floor which has a soothing effect and the

bubbles from the intake swizzle up my spine.

Silver, our tom cat, is having a moan at another tom cat out the back and it is like cries of pain in the rain. It takes me back to when I was very, very little.

I float free and go deep. Deep into my babyhood. I am parked on the big double bed with the other babies while the parents have one of their parties. I am swaddled. But there is pain. And I cry and set the others off. It is incomprehensible to a little baby. It hurt. A wrong pain.

Now to around 4 years old. I have tied myself up in the baby's reins so I cannot move. And I am imagining, acting out the pain. I fall over and strike my arm on the iron claw leg of the big table and both bones break so my arm is hanging from above the wrist. And all I feel is guilt because I have been doing something I shouldn't. It is wrong to be doing things to myself like that. Yet I was just trying to follow something through, to work out what was happening. But somehow it is wrong and I am guilty for what was wrong. But am I?

And the dreams - or rather the semi-dreams before going to sleep. The ritual "What say one day where I have to act out being hurt sexually before going to sleep". But I have to be able to control it, control the amount of pain and fear. I don't know how long those dreams went on for. I think it was all about controlling the feelings, trying to make sense of them. I don't think they were sexual at all. They were something deeper.

And more and more memories as I got older and older....Scary things, things that weren't right. But I bury them deep. But always the guilt. I was

doing something I shouldn't. Nobody else did it. It was wrong. I had to hide away. Yet it was compulsive. I had to be able to control the feelings, control the pain by causing more pain in a way I could just about handle.

My periods started on Anzac Day when I was just 13. It was the Girl Guides parade. I had to be dragged kicking and screaming into puberty. I wanted to be a boy. I wasn't interested in what the girls were interested in. I liked the natural world and even had my own bug-house in the old chook shed where I kept my shell collection and made dyes from plants. However, I tried to join in with other girls. But just when I should have been having fun with a group when we were on a horse-riding holiday, I got a really heavy period and flooded - very embarrassing. Is this womanhood?

And then I got eczema all over my body. I had had a small patch and was afraid to tell my parents because they had said I would get ringworm if I played with the cat. It got worse and I had to hide my forearm so I couldn't change into my short sleeved shirt for PE and had to keep making excuses. One day my mother saw it and took me to a skin specialist who gave me something which made it flare up all over my body. I was like a burns case and admitted to Wellington Hospital just before I was due to sing in the mixed secondary school choral concert. I was broken-hearted as I love singing. My period came and they gave me a T-bandage and no help at all about what to do with it and I was already embarrassed, being so young. I then had to deal, alone, with a woman with a severe epileptic fit as I

was in the adult ward and it was ages before a nurse appeared. It was all a bit much to cope with.

We moved up to Auckland. I couldn't even say goodbye to my classmates at Wellington Girls' College as I left straight from hospital. I looked a sight with the eczema and found it hard to fit in. And the itch was terrible. I went through a whole jar of tar ointment in a couple of days. It probably wasn't very good for me, anyway.

Then started the blanking out episodes. All through my teens. Sometimes they were related to sexual encounters as I was learning about boys and I couldn't cope with this - though sometimes just to do with an unbearable stress. Sometimes it seemed from nothing at all. But I was afraid. Yet my body yearned for something from long ago. Yet I was scared of it too.

I started having terrible nightmares where I thrashed around in terror and cried out. I know it scared a friend of mine at Ranger camp. I was full of fears and very shy. It was difficult to make relationships. I was very confused and alone.

And then I had unwise encounters in my late teens. I was ashamed and didn't really want to. But somehow it was the only way I could gain acceptance or closeness. Yet it was a lie and I hated myself. Again, it was despising my body, not treating it as something precious, almost trying to hurt and damage it again. And again the guilt.

There came a quiescent time after I met Brian. He, too, was concerned about my reactions. I learnt to be calmer. But sometimes I would dissolve into violent sobbing. I couldn't play tickling games or

watch him play with the kids. I would just freak out and sob uncontrollably. Laughter almost invariably turns into racking sobs for me. So I have learnt not to laugh deeply.

And then a few years ago, I was very low and everything was bad here. I started hurting myself again badly. Again, guilt and shame. Also bothered that I was deceiving Brian. It is as though I became more and more destructive of myself, almost suicidal, and I couldn't help it somehow. It was more and more compulsive as I felt more and more despair about life in general. I had no place or purpose and seemed to be rejected by everybody.

Maybe destroying myself - or the essence of myself, which is how I look on my womanhood - was the ultimate acting out of the way those who should have cared had treated me when I was young and so vulnerable. I might as well destroy myself. I didn't rationalise it like that at the time. But I guess that is what I was doing.

And perhaps that is why I have cancer now - a self-inflicted injury. How ironic!

Remedies



As I lay in a deep trance in the spa, I felt the way to release all this. I could feel the guilt floating up from my body into the water in the order in which it had appeared. Strange how even a very young child realises somehow that some sexual acts are wrong. It will take quite a bit to make it all go, but I made a start tonight. I could almost feel a lightness in the womb. I must let it all go.

I got the baby things together tonight, with no pangs really, to give to Kellie and Les. Always before it had hurt me so badly. I did so want to have a child with Brian and losing that baby was the hardest thing. I had always thought I would have another. But it wasn't to be and I felt betrayed and cheated. Still, I now realise that I am too old and tired for it to be much pleasure. Part of it was for the experience of giving birth again. The birth of my first daughter, I missed because they had sedated me too heavily as my blood pressure was rocketing. Partly this was because I was distressed at being isolated from my husband just when I needed him. I was extremely depressed and his made bonding so difficult. I just wanted another baby quickly but had countless miscarriages. The eventual birth of my second daughter, after a rather insecure pregnancy, only carried to term by the use of progesterone injections and complete bed rest, was so quick that I almost missed that too. I

did not feel I had experienced childbirth, as though I had missed out on something terribly important to me. This has had repercussions ever since. That is all bound up with this whole sexual thing. But that is the wrong reason to have a baby.

I felt I needed to write all this down while I was still in a relaxed, post-trance state. It just seemed to flow. It is amazing how calm I had felt while thinking of these things. Usually they provoke a near panic attack and my breathing changes. Now it is still calm and controlled. That is progress, at least.

Anyway, I have to caress my cervix, treat it gently, love it and cherish it. The brutal treatment they are proposing will just add insult to injury. It has been damaged enough. I have to apologise to it for the brutal treatment at my hand and at the hand of others. I need to feel and see it beautiful, whole, healthy. It has been treated badly and I need to make amends.

I need to feel the vault lifted up and young again, feel the cervix, stroke it, love it, cup it and feel it respond. I cannot easily do this for myself, but it is important that it is acknowledged. I will have to do it mentally but that is not quite the same. I need to get over the guilt and fear of penetration, to feel that it is OK, that the penetration is to caress the cervix instead of hurting it. I do not want any sexual arousal, but I do need to have that part of my body acknowledged as being OK and healthy and beautiful. That is what would help most. I am a little afraid of that. But I will try. And I will release all that guilt which is lying heavy on those parts.

And maybe this would also help the detachment I often feel between the sexual response in my body and my mind.

And doctors comment on the prolapse and I feel guilty. Perhaps I have done it to myself. And it is no longer beautiful, no longer a part I am proud of. They see it as a sign of old age - just sagging from childbirth. I had two very easy and short labours, but decent sized babies. But I also think it is the direct

response of what happened at a very young age - and my immature reaction to it. I do not want to feel like this. I want to be beautiful inside. Yet, somehow that fount of womanhood inside me is the only thing I have to hang onto. It is where the pain comes from but is also the very essence of me. And I must learn to love it, no matter what state it is in. Only that way will I heal completely and learn to love myself totally. It is a hard lesson.

I was a little child who could not make sense of what should not have happened to her. And in acting it all out to try and control the feelings, I have continued the brutalisation that should never have happened. Now I have to reverse that. In some ways the cancer is the ultimate in self-harm of that part. My body is attacking itself. It is ironic. So I have to put a stop to it. Be gentle with me.

A deep breath. And suddenly I was here again and shook off the trance. I felt so peaceful. But I knew that this is the way forward, the way to free myself and allow the healing to take place. But I will need some unconventional help from someone I can trust.

I am afraid, yet somewhat joyous. Above all, I am calm again about it. Maybe I will beat the cancer. Maybe not. But one day, sooner or later, I will die whole - in body and in mind. I will be integrated at last.

12.45 am

I am trying to free myself from the guilt, the feeling that it is the things that have happened to me in my life and the way I have reacted that are in large part responsible for the cancer. I do not know what the shadowy memories were. However, they were ever present during my childhood and still surface at times of stress.

They say that cancer often shows up in the most vulnerable part of the body. I would say this is true with me. I always used joke with my girls that I would die with all my bits, thinking mainly of breast cancer. However, that still applies - and perhaps even more so to the cervix. To me it is the part that centres me. Amputating it would be like amputating a limb, only worse because of the emotional aspects.

This time in the spa was very freeing emotionally. I think I should make more time for this, setting the scene with our soft red lights powered by a car battery so that there is just enough light to see, but the stars are still visible because the eyes are not confused by the red lights. Total relaxation and total washing away of negative feelings do help. It doesn't really matter what happened in the past. It is for me to allow it to flow away now and to feel clean and calm.

Doctors have no idea when they say "Oh, I can't find your cervix because of the prolapse", that it just like saying "Oh, you have got such saggy tits!" Just because it cannot be seen easily does not mean that the cervix is not a beautiful and vital part of a woman's self-esteem.

Relapse



A year or so somehow went by. Life did not get any easier nor the stresses less. I tried to keep up with my diet but found it increasingly difficult. It is not much fun cooking two separate meals. I kept up a reasonable regime of supplements, but occasionally I felt I just didn't want any more as I would feel a bit sick.

I still kept up with my Qi Gong and did a concentrated course to learn more about it. This was most helpful and focussed my energy much more on this. I found it very relaxing. However, it is quite time-consuming to do the full exercises and meditation - but I did try.

The hardest thing with using alternative therapies is to keep them up for such a long time – probably forever. But I just had to remain quietly confident and keep going as best I could, trusting that I could overcome this problem.

April 1st, 2003

April Fool's Day, and something made me ask for another routine smear test with my GP. It may or may not be a reliable way of checking on the cancer. Most of the tests come back OK but I have my suspicions. Anyway, it does mean that he can keep a good check. That caused a lot of bleeding. That doesn't

seem a good thing, was the comment. Perhaps we'd better send you back to National Women's and see what is going on.

Damn! That is a setback. But then, I hadn't been feeling brilliant in the past few months, with a general unwellness. But I had worked hard and got all my autumn vegetable planting done, which had made me feel good. My peas had just started showing through, I'd thinned the carrots and planted parsnips. The cabbages, caulis and broccoli were all growing strongly. This is my relaxation, as well as ensuring a supply of totally organic vegetables. There is nothing nicer than going down in the evening and choosing just the right leaves and roots for dinner.

However, I had recently had a major falling out with my younger daughter which had distressed me desperately. I tried not to let it affect me, to only allow the emotion to go as far down as my waist. But something as devastating as this would surely affect all of me. I know just how badly emotion can affect cancer and I was worried. And I was due to fly off with her to Napier for my parent's wedding anniversary on the last day in their old house and then to help them move into a new home in a retirement village. It was all such a worry.

That is the trouble with cancer. You can be sailing along, confident and happy, and then, wham! It just creeps along, unseen, unfelt. And emotional upset is about the worst thing for it. I think it acts like a fertiliser and sets off a period of more rapid growth.

The next day, though, I went for my usual Qi Gong treatment and came home quite tired but enthusiastic about beating the cancer. Energised, I spent a busy day in the garden the next day, clearing a trailer-load of old plants and prunings. It was fine and sunny but the big clouds all the time meant that our pool solar heating didn't work brilliantly so it wasn't that pleasant for my daily swim.

I need sunshine. I have so much energy in the sun, or even on a clear night. I don't even mind the rain. It's just the hanging clouds that we seem to have here all summer that distress me. It is brilliant in the morning and I feel all invigorated. But by 10 o'clock when it has warmed up, the sky seems to suck up half the Manukau Estuary and it just hangs over here, blocked by the Hunuwas Ranges to the south of Papakura. So frustrating and enervating. The day's work left me really tired, but content.

Over the next few days, I had more bright bleeding and the low pain got worse. Is it my new Chinese medicine? Or is it a period? Or is it - please, no - that the cancer is indeed getting the better of me? To cap it all, on the Friday, I lost my wedding ring. It had been too tight so I had put it onto my little finger. About midnight, I noticed it wasn't there. That meant that I had now lost both my engagement and my wedding rings. I remembered my mother had done the same. I searched everywhere, but it has never come to light. What a week!

Sunday, Miranda and I flew down to Napier in the little "pencil case" plane. "I can't go in that! I'll be sick" she said. I concentrated on my meditation and Qi Gong all the way down, worried about my cancer as I was still very unwell. This was the worst I had felt since my diagnosis. Was it going to get the better of me? I was determined it wasn't. But my energy was low.

It was a difficult situation, being with my sister and parents, as well as my daughter, trying to pretend I was OK so they wouldn't worry. We were all busy and working hard,

clearing up and scrubbing the house. It was the first time we had all been together since 1995 and it was good to be able to chat. I was hurt, though, that not once did my parents ask how I was. I know they were preoccupied with the move, but that did hurt. I had not yet learnt to let these things wash over me and so it was in danger of exacerbating the cancer. Stupid the way we let these things bother us so much.

By the last night there, I was really unwell and lay awake from 3.30 am worrying and crying after Brian had cruelly commented "Out of sight, out of mind" to me on the phone as I hadn't been able to contact him as much as he would have liked. Perhaps he was lonely and feeling what it would be like without me. And I was with my family - and his are mostly estranged. I know the thought of losing me is so difficult for him as we are very close, so I do try to make allowances.

By the time I got home, after five days away, I was shivery, with a watery loss. Brian gave me healing and I immediately felt the benefit. By the next day the bleeding had stopped. But it did recur on an off over the next few weeks. And each time it made me so worried.

Tuesday, 15th April

Really nervous about a colposcopy appointment at National Women's. My GP had managed to get me one urgently. I did a long session of Qi Gong exercises before I went, to settle myself. I didn't have my usual consultant but a very gentle Chinese oncologist. It looked grim. You can see on a TV screen what the consultant can see through her instrument. They swab a dilute vinegar solution on and any doubtful areas will turn aceto-white. There it was - all white with prominent blood vessels.

Whew! What to do now? I had never seen it like this in all my colposcopies. Always there had just been shiny pink with the occasional redness. Obviously this cancer had taken off in a big way!

I had a long chat with the staff nurse on the way out. She was very understanding about the way I had been trying to treat my cancer. Together we wondered whether I had delayed this long, just to give myself enough time and enough strength to go through with surgery. I know I couldn't have done it before.

Almost decided to have a simple hysterectomy - not a radical one under any circumstances - if they will do it. If not - then nothing. I still feel so strongly about the destruction or interference with my immune system and, to me, taking out all the lymph glands would do that. Then most probably I would be left with swelling in the legs and, quite honestly, my life would not be worth living. It is still quality of life rather than life itself which is important to me. However, my pendulum test still says No. So I'll sleep on it and talk to my GP tomorrow.

Anzac weekend and a short break to New Plymouth, courtesy my Fly Buys hotel voucher. It is good to get away, even though it is a hassle organising the animals, etc. Brian doesn't seem very bright and has had to stop several times on the way down to rest. He has a really bad pain and doesn't want to go out for dinner. I'm worried about him.

Still more pain so we didn't go to the Anzac service at the Cenotaph as we had wanted, but we went along later and then walked on the beach front. If it is not one of us sick, it is the other! Maybe we

neither of us has much time left. I will have to drive home as he is in no fit state.

I had to be strong for him and seemed to gain strength. April 30th and I am feeling so happy and confident. I can feel life swirling round in me. The white fungal problem between my toes is going, just from concentrating. Maybe the cancer will all be OK. I feel confident anyway. I am sure that if I can make the fungal infection go, that will be the start of the cancer going.

The oncologist has organised an ultra-sound for the 5th May. This is always a trial as you have to have a full bladder. It means drinking a couple of litres and then joining the traffic into Auckland. Each jerk of stopping and starting is agony. And there were all the pregnant women for their routine scans. It just brought it all back to me - how I would love to have had another child. And here I was, too old, with that particular bit of my anatomy in danger of killing me.

Strange - the ultrasound showed up nothing worrisome, though the technician was not particularly helpful in pointing things out to me - unlike previous scans. So there I was, relieved in a way, but still puzzled by what I had seen on the colposcopy screen. I am not sure what to trust. Mind you, it just shows the difficulty of accurate diagnosis of a serious disease.

The next few weeks were a time of renewed effort. I had read that elevated temperature could help and that it would be good to have very hot baths. I started a series of these every night, gradually taking the temperature up to 43oC. It is

quite debilitating but I felt good. Further worries with Brian as he had to go and have a colonoscopy for his pain and it showed colitis. That means that we need almost totally different diets. It is bad enough thinking about every meal and working it out round his likes (he is a traditional meat and two veg man) and the way I would like to experiment with new foods and ways of preparation. Now it is double the trouble! Oh, well, these things are sent to try us.

Brian then got flu. Worryingly, I have got a slight snuffle and sore throat too. With the amount of supplements and Vitamin C I have been taking, I shouldn't have succumbed. It means that my immune system must be really struggling. That is a worry. I don't usually get colds and flu. However, when I did get a fever, I left it untreated, hoping that it would at least inhibit the cancer.

29th May and an MRI to check what was really going on. I am still off colour from the flu but reasonably calm. I am used to these things now as this is my third. I had to ask them to put a towel over my shoulder and neck as there is a freezing draught from the ventilation in the tunnel. Reasonably confident, though.

4th June and off to my GP for the results. I always have them sent to him so I am forewarned before a specialist appointment. I can rely on him to be honest and to help me. "You've got a tumour 37mm x 31mm x 25mm!" he said while reading through the report.

"You're kidding?" I replied

"No. I'm serious. Look at this. Do you want a copy?"

Hell! What do I do? This is infinitely worse than I had ever imagined. I had felt I was doing OK and here the thing was growing fast. There had been nothing visible on the ultrasound or the previous MRI. However, the hospital had managed to lose the films of that one so there was only the report. I was very calm and discussed the situation with Ric. He felt they would really press me for surgery now. I am due to go tomorrow. Things don't look good.

Discharged!



The appointment with the oncologist didn't go at all as I had thought. We had been asked to come along to the daytime clinic whereas I had normally seen him in the evening at the colposcopy clinic about 7pm, which was really convenient. It was always very relaxed and I felt very much at ease, in spite of being strung up in that wonderfully inelegant way they have in gynae examinations! He would always explain what he saw and seemed reasonably confident. However, he always gently pushed me about surgery.

When the results of the ultrasound scan had come back, I had gone to the evening appointment but not had another colposcopy. I was sad about this as I always found these very helpful. Everything is magnified on the screen and Brian would photograph some of the pictures so that I could have a record and also something tangible on which to base my visualisation. The oncologist was always very helpful about this. He asked that we go along to the daytime clinic so that we could meet the radiologist and have this option explained. This was the second time this was supposed to happen.

As soon as we walked in, my consultant said "The team has decided that you need radiation and chemotherapy. We've discussed your case at our weekly conference." I was stunned. I asked about surgery. "No - too late for that now." Then I asked

to see my MRI scans which I had been promised. They were not available. The radiologist was also unavailable. So the whole point of our coming at that time was wasted. I was confused and upset.

I asked about another colposcopy which was so helpful to me. "No point." I tried to protest and say that there was a point for me, if not for them, and explain how helpful it was to me to be able to visualise my cervix.

"And what about after radiotherapy? Do I come back to you then for regular colposcopies?"

"No. If that hasn't worked, then there is nothing more we can do."

Gone was the ease and friendliness I had come to expect from him. He was so abrupt, almost dismissive.

Great! I had been told that they followed up everyone with colposcopies. It felt as if I was just being abandoned because I wasn't playing their game. The system was trying to take me over.

He tried to be kind, ushering me out with a hand on my shoulder, saying "We'll see you again in the future - well and happy."

"I don't think so....." I was in shock. This was to get worse when I glanced at the form he had given me. "Discharged!"

That meant that he had just dismissed me, discharged me. It was too late for his services and so I was just being dumped onto somewhere else or left to die. I hadn't followed his advice so he washed his hands of me. I was devastated. This was the one really human face I had found in the whole system and now he was abandoning me.

When the realisation of this sank in while I was in the corridor outside, my legs suddenly felt as they were giving way. A nurse took one look and ushered me into a side room. We had a long chat and it was left that someone from their social services department would telephone me.

Depression really set in now. I had been pretty well OK until this point, in spite of all the pressures, all the decisions and all the worry. Now I was abandoned. I couldn't eat or drink or do anything. There seemed no point in anything at all.

Someone phoned me and I tried to explain why I was so distressed. I needed those colposcopies as visualisation was my strongest weapon. But I was being denied these as the powers-that-be felt they would be no use. They weren't prepared to see how I was trying to help myself. All they wanted to do was attack the cancer by poisoning and burning it. I wanted to try and gently but strongly separate it from my body by using the power of my mind. And I knew I could do it - or rather, I had known I could do it. Now I was so depressed, I couldn't do anything at all.

Saturday I had made an appointment to see my GP, Ric as the last patient. I was very very distressed and near collapse in the pharmacy, sweating and faint. Ric, bless him, said "Here you are! Reading material. Let me know what you think!" as he gave me four books he had brought in for me. I handed one back, telling him I already had it, Ian Gawler's *You Can Conquer Cancer*. He spent a long time talking to me, calming me, going through options. He even missed his dancing class to help me. That is a really caring doctor.

Exhausted, I slept in the sun most of the afternoon which must have been very therapeutic. Then I went down to Tuakau with Brian as he had to go and check something on the waste water treatment plant he manages. It was good to get out and take my mind off things. I wandered down to the ponds with him and watched the birds swooping over the surface. It was a lovely evening and I started reading one of Ric's books by Dr. Kelley, *Cancer - Curing the Incurable*. I could see it would be a very hard road - but worthwhile. And others had done it before me! By the end of the evening, I was more relaxed.

Sunday, I felt much better after reading Ric's books. I made a note in my journal: *I think I have reached my decision. The anger is passing, but I'll still send the letters.* This was a reference to a letter I had written to the consultant, expressing my concerns but also thanking him for his care to date. Brian had also written a letter, more critical and angry but, as he said, he felt they had let me down badly. They had said I could see the MRI and they had made decisions about me arbitrarily. It was as if we had never ever had the evening discussions at the colposcopy appointments. Were they just humouring me until they could persuade me to see sense?

I decided to try the other thing Ric had suggested - coffee enemas. It sounded pretty grim. I had read of these in various books and rejected the idea. However, the time had come when I had to make some changes. So I dismissed my husband and told him I wanted some privacy while I tried. Amazingly, it was OK and it is also amazing what rubbish the human plumbing system seems to gather! Incidentally, I have kept up with these and they are a very important part of my healing plan.

The theory is that the caffeine is absorbed into the portal vein through the bowel wall and carried up to the liver where it stimulates the production of bile and the liver lets go of all its toxins into the bowel and it is then evacuated. The bile also is evacuated instead of being reabsorbed and reused. This means that the load on the system has been reduced and the liver can pick up another load of by-products of metabolism, and other rubbish from the bloodstream and process these. This, then, allows room for more to be picked up from, say the cancer. I must say that after a coffee enema, I always feel so much better. My skin and eyes are clear and any headache or general tiredness seems to vanish. It is the mainstay of my cleansing programme.

Brian has helped me by rigging up different valves and my elder daughter, Nicki, got me a proper bag as a gift - see the sort

of presents you get when you have cancer! I find it most relaxing to have a hot bath and use the enema at the same time. This avoids problems with leakage and it is really relaxing. Brian calls these my "coffee mornings". A new spin on an old expression for women spending time on themselves. No, really, he is most supportive and I am lucky!

A new lease of life! By Tuesday I was much more hopeful and gardened all afternoon. Planted beetroot while hoping it will be more successful than last time. Then I replanted the strawberries and rhubarb. The garden is so therapeutic. We have tall trees at the back of our section and they are a mecca for all sorts of birds. The air is filled with their song, especially in the evening when the low setting sun lights all the trees up a deep golden colour.

I am cultivating the back of the section next door in a neighbourly arrangement where I use the land and my neighbour can take what he wants of the crop. This means I have the space and also a better growing situation than under our trees. I spend hours with my bare feet in the earth, weeding, planting, just walking and observing.

I miss my allotment garden from England. There I had two large plots and a shed. I worked on them every night until gone dark. They used to call me the night shift. Brian was working away and this was a really good way of spending the lonely evenings - except they weren't lonely. Robins would hop around my spade.

There was a young fox who came and shyly played. He had a penchant for shoes and one evening I made the mistake of taking my shoes off by my shed and leaving them. When I came to go home, they were missing - and they were good soft leather ones, too. We were always finding odd shoes in the blackberry patch beside the allotment. This fox was really playful and one evening I watched him playing with the pile of used straw from

the local stables that I had piled on one corner of the patch. He picked up solid bits and tossed them in the air.

I would get pounds of strawberries and other berry fruits. My red currants would hang like translucent jewels on the bushes. It was a bit of a battle with the birds and the gooseberries, but we had enough. There was always far more than I could eat so the neighbours did pretty well. All the old men in our little area seemed to have been widowed. It is usually the men who go first, so there must have been something in the water - or in the gardening! They would tend their plots and give me extra seedlings and I learnt so much from them.

Yes, I really miss that. There was so much more I could grow there than in the Auckland climate where we have so many diseases on the plants and none of the berry fruits will grow properly. They need a good cold snap which we don't have.

Still, at least I have Allan's patch, for which I am grateful. And it gives me great pleasure and a supply of uncontaminated food - something which is hard to find these days.

June was a month where I was consolidating my efforts at helping myself. I was having one to enemas every day, trying to watch my diet, resting when I needed and trying to get out in the sunshine which keeps me from being depressed. We lost a litter of kittens at a month old when a stray dog came into the garden and killed them. Only one was left - now called Solo. This sort of thing was hard for me to deal with. However, we added them to our ever growing cemetery.

I seemed to get more energy and did things like clearing the kitchen cupboards. All the grain products seem to have horrid moths coming from them shortly after purchase. I think they are a kind of weevil. They hatch and then infest anything else, making cocoons on the outside of packets. It all needs sorting and cleaning regularly. Even if I put everything in sealed containers, they are still infested. I continued my gardening

work and clearing the section which made me feel better and we took a couple of loads to the dump. It seems to help to get the general environment feeling good.

I continued reading all sorts of books on cancer and healing and diet. I read about Cisplatin and thought Definitely not! I made an effort to follow the Kelley diet but it is difficult, especially as Brian couldn't live on it. I have a feeling cancer is a bit like diabetes. It is for life! And all the changes have to be for life, too. The hardest things are the dietary changes. I reckoned I would probably have to give up beef - really difficult as I like it and it is Brian's favourite. He most certainly can't go without meat. His metabolism just wouldn't cope. However, I was improving and Ric commented that I looked a lot better and my face wasn't puffy any more.

By 20th June, I had written in my journal *Feel really happy and at peace - joyous really!*

Radiation?



I never had the courtesy of a reply to my letters to the consultant (unlike the lovely letter I had received from the surgeon in Melbourne) but was promised through the social worker that, once I had gone to see the radiation oncologist, I could come back and have another colposcopy.

My appointment was scheduled for 2nd July, early in the morning which meant fighting through the rush hour traffic. I am definitely not good first thing in the morning and this was an additional strain. I was pleasantly surprised at the Oncology unit at Auckland Hospital. A real effort has gone into making the waiting area as pleasant as possible, with an atrium and plants.

I became really distressed during the appointment. The oncologist went through all the pros and cons of treatment but I suppose I really felt hostile. I had been sent back to see the oncologist I had specifically requested not to see. To allow someone to effectively poison your system, you have to have total trust. This had been broken at our very first appointment. You can't get that back. It may be illogical. But I just did not trust. I went through my prepared list of questions and then asked about seeing my MRI. The surgeon had said the radiologist would show me as it was more in his line. But he

didn't seem to want to show me either. It was really important for me to see it, to gauge the extent of the cancer, to see the reality of it.

Eventually, after I had broken down and sobbed, he flicked on the computer screen and pulled up a few images. Brian managed to get some photos for me which were meaningful. Why do they have to be so secretive? It is my body. And I want to have a choice about what happens to it. None of this makes me trust the system or anybody in it. *(The hospital has since managed to lose this MRI completely - which also makes it even harder to trust them. With the lack of cooperation shown round this time, I begin to wonder if it is not just another instance of information being withheld?)*

I agreed to go to the Cancer Society where, each week, they give a presentation of the procedures involved in radiation treatment. We weren't impressed. However, these are really lovely premises and I can see how it can really help someone going through radiation or chemo treatment to be able to stay there so handy to the hospital. Unfortunately, all the books on cervical cancer were out of the library, but I browsed for a while.

Really, I was no closer to making a decision to undergo radiation treatment. I still didn't trust the system or the outcome. I had always been on the smaller percentage, the ones for whom things had gone wrong. Why should that pattern change now? And I would have no control at all.

I let things ride. I had not signed the authority for them to give me radiation and so nobody came back to me. That suited me. I was not happy with it at all. However, it was really scary going it alone, although my GP was very supportive. We discussed all sorts of complementary things that I could do. He advised on supplements and often gave me interesting papers from journals he subscribes to.

"Read this, and see what you think about it" he would say.

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I would see him weekly, which was a good boost for me. He kept me from slumping and always tried to keep me positive. But it didn't always work. I was so up and down.

Despair



Saturday, 2nd August 2003

I really don't think either of us can continue like this for much longer. There is nothing to live for. Our coincidence work comes to nothing, in large part because there is absolute silence, apathy, almost a blocking. Nobody at all will even look critically at it. The most they will do is scan it and say, "Interesting" or some other such watery comment. Or, worse, they will look at just one small part of it, rather than as a whole, and say it is rubbish. It isn't just the cancer that is stressing me. My whole life circumstances make me feel so alone. But I must keep on going.

If we didn't feel it was worth it, we wouldn't have devoted our whole lives and resources to this work. But we work utterly alone. The isolation is killing us. I read about all the researchers in the cancer field and how they have suffered and there are strong parallels. But at least they are peddling something that people are desperate for, will pay anything for. We are trying to show the worth of life and that it really does matter how you live it. We are trying to show the reality of God and that there is a Judgement and appears to be a continuation of the

spirit after death. You would think this should have a relevance to each and every one of us. But no! People are afraid to look at such questions and so we are frozen out.

So many researchers in new or unorthodox fields have ended up killing themselves. I fear that will be our end too. There is little point in continuing. It is as if we don't exist anyway. We are totally isolated and each attempt we make to break that isolation, to be part of something, turns sour and we are even more isolated than before - university, choirs, church, community effort, etc. What is wrong with us? Is it just that we don't just accept, uncritically, anything we are told by authority? We are certainly not PC or right-thinking. But that would mean ceasing to exist as an individual.

I feel I am dying. I haven't felt it before. However, since my stay in Middlemore with that chest pain, it has become ever stronger and I am afraid - not of dying, but of having not accomplished what I need to. And I actually like the natural world. I get a sense of peace in our garden under the trees, listening to the birds singing. But ever since the episode next door where we are now in danger of having the section turned into a couple of units, I have lost all will to live. Before that I was happy and confident I could beat the cancer. I had found out I could keep chooks and even a goat. I wanted to put in more fruit trees and grow all my own vegies and herbs. And I was at peace.

Now, whenever I hear my neighbour working on his house ready to sell it, I despair. I am under constant stress because of it. We could have bought

the back section - just. It would have added little value to our place but Brian was prepared to do it for me. Perhaps we could buy the house if he wants to sell. I would love to have a centre. We would have to do a hell of a lot of work on it and quite frankly, Brian is sick to death of building work. We have to do it all ourselves because we cannot find anyone reasonable. Look at the problems we had with our new library, getting the slab done, and the tree-cutting and the plastering!

This whole area has been subdivided by greedy entrepreneurs who just take the money and run, leaving rental properties filled with noisy, uncaring tenants. I am loath to just sell up ourselves and go, after all the work. And I haven't the energy. And where would we go anyway? I suspect we will leave here in a box. I don't think I have that long left, anyway. I keep having the chest pains. And I have a low left sided pain all the time on the pubic bone. And then there are the lumps in my tummy. And now there are two more lumps at the top of my spine. I don't feel well. There is something wrong and I don't know what.

There is nothing I have had to do with Auckland Hospital or the pathology labs that inspires any confidence in me at all to go ahead with the radiation. I just cannot put myself in their hands in something where it is critical they get it right. My experience says they will cock it up totally. But I am afraid that the cancer is growing. I can feel it to the left and the stress I now feel is not helping. But what can I do to help myself? I feel totally lost. There are so many "cures" out there and so many of them are either

anecdotal or somebody is pushing them to make as much money as possible as fast as possible out of other people's fears. I don't want to touch anything that has the stench of money grubbing about it. I know some things are expensive to manufacture and that nothing comes cheap these days. But some things just reek of conning money out of the desperate. I would rather die than be part of that. And maybe I will. But I loathe money grubbing with all my being. Nothing will turn me away faster.

I feel abandoned and alone. My first GP's response was a disgrace. He just wouldn't help me. I was pleased to find Brett and felt led to him. I followed everything he asked and even offered to let my case be written up for their research at NHL. I got a really snotty response from the secretary there and have been turned off them since. Brett was fine at first and then suddenly didn't want to know. He asked me to come back with blood test results, etc. but he did nothing. I felt pushed aside by him for no reason.

I feel really let down by the naturopath I went to, after being short-changed. I cannot go back there as I feel uncomfortable with the receptionist, even though he was right in various aspects, even saying that I had parasites but I only just remembered that this morning.

The surgeon had seemed decent but he hadn't even the courtesy to send an acknowledgement of the letters Brian and I wrote to him - a bit different from the approach of the surgeon in Melbourne. That has hurt me deeply and I have now written him off and feel that he was only being decent to me to

try and persuade me to have their treatment. I feel the Radiology lot are just trying to "sell" their treatment. It has that feeling.

Ric tries, but is a little lost himself. And he is a bit too keen on some of these American treatments. And he doesn't listen when I go to him needing to talk and understand, but just digs out the latest theory and sometimes I come away feeling even more lost, having been unable to express myself or talk about what I went there for in the first place. But at least he doesn't pretend to have all the answers.

And as for God..... Well, I had always felt guided and led and that if I did the right thing, I would be helped. That seemed to be the case in England. But ever since we came to NZ, it is as if God is powerless. There is not one thing we have done that has worked. We write off into a void. We meet people and are friendly and open, socialising or doing business. They seem OK and are friendly back but then the next time we have dealings with them, they are hostile or have turned cold or devious. This is especially so with journalists, etc. who are interested in our work but when they talk to someone else, they change. It is very disturbing.

Even my friends.....Angela seemed to want to understand and even helped with coincidences. We spent a lot of time with her, trying to help her understand. And now she has switched - just like that. She was my only friend. And she is now vicious to me.

And the electrician who was so decent and right, the way we found him and who did such a good job - when he talked to the elders at his church, he

has been warned off and he was really cold when he came back for the certification.

And the Christians.....!!!!!! They are the worst by far. Look at them at Mt. Albert and here in Papakura! You try to help, to be a part, but find you are just frozen out or worse. The isolation is terrible.

And Simon.... Well, he tried to help but got himself all caught up in transference and counter-transference. He actually listened to Brian and even asked if he could come round again to discuss things. He invited himself for dinner but then didn't turn up. His wife didn't like it. He has let me down so badly. All he could say about my cancer was that it was an STD. He has not even given the support of a friend - which he claimed to be.

So who can I trust? I try to trust God but He lets me down again and again. I don't even ask for anything. But every effort I make is dashed down again by others. I know they have free will and God will not take that away from anyone. But you would think He could just make something work! The devil seems to have a much greater power now than 10 years ago and that is why people change. Possession is a very real thing - but most people would scoff at it and think I am crazy to even mention it. That is why people switch as they do - normal and pleasant one minute and then suddenly the opposite.

I know that if God intends me to live, then I will, as long as I try to follow what is right, what I am being guided to do. I also know that if He intends me to die, then that will also happen - maybe not how I think, but in a manner of His choosing.

But somehow I no longer have the energy to try

any more. I have done as He has asked for so long. I have used up all my energy. I am becoming weaker and weaker, as is Brian. There is nothing to keep me going. I need acknowledgement - be it ever so little. And there is none. Brett didn't acknowledge me, gave no encouragement. I had followed his regime and then I was on my own. I can get no acknowledgement through orthodox cancer circles that what I am trying to do may have some benefit as I am trying to treat my whole being, not just a bit of me. I get no acknowledgement from anyone in anything I try to do. My family don't acknowledge me or even try and understand what makes me tick.

The above was written at a very low period. It wasn't always like that. I had not been well and things seemed very bleak indeed. Brian was under a lot of strain and snapped easily which didn't help me. This is the sort of strain felt by partners of those with cancer or any life-threatening or degenerative illness. But I couldn't say APlease don't be like that as it's bad for me.= That sounds like a sort of emotional blackmail. So I have to find ways of deflecting his feelings from myself to protect myself. But I am always affected by his mood and concerns because we are so close.

There is the worry over the way the cancer has grown and whether I will manage to get through this. What will happen to Brian? Would he cope with his loss? These thoughts turn over and over in the mind.

And all the time Dr. Chen is saying "Too much thinking - no good. Still doing your Qi Gong exercises?" I always came away from my sessions with him feeling much more balanced and at ease. But all the time there is this background worry.

And then there is the concern of the expense of all the

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treatments. Brian has limited paid work and if he loses any of that, we are really stuck.

Somehow, though, whenever I go really down, I do bounce back, perhaps stronger than before.

Trapped in the System



In spite of setbacks, I kept trying with my diet and then decided to undergo high dose Vitamin C therapy. First, though, I decided to a full cleanse before I started and so took a two week course of herbal preparations.

Right in the middle of this, we got a chance to go back to England for a short visit. I had 36 hours to decide, pack, sort out my house and animals, and get to the airport! No time to worry about anything. Brian went back to a Gaudy at Oxford in early October where the old members of the College come back to a dinner, held only once every 11 years for each year of coming up. I took a bus up from Oxford to Birmingham where I was able to stay with my daughter on her canal boat. I had phoned her and asked her what she was doing next weekend. She said "Why? Are you coming to see me?" She said only her mother would just turn up from the other side of the world at such short notice.

The stay in Britain was interesting, and the highlight was going back to Conway which was special for Brian and me and spending the night in the car right out in the country up the Conway Valley by a little railway station. It was like paradise. I walked along the track and found we were near a pipe bridge over the river which is wide and peaceful at this point - almost primeval and all misty. The pipe supplies water from the Welsh

mountain reservoirs. We picked ripe blackberries for breakfast and sniffed the fresh air. I loved it. The only problem was that my cancer suddenly started to play up and I bled again which made me scared.

However, I wasn't going to let that ruin my day. We went into the town itself and had coffee right in the walls of the castle, looking out over the bay. Bookshops, of course. And then I found a little infuser in the shape of a teapot in a shop specialising in teapots. This was perfect for making my herb teas. You can put them directly into this and there are no bits to sieve through the teeth. I like to make my fresh herb teas in a proper ceramic teapot and make it a pleasant civilised experience of taking tea rather than just rushing through the drink.

The end of the day was wonderful. We went up the Great Orme, a huge bare headland, and watched the sun go down over the Atlantic Ocean. But was it setting for me? These moments are so full of emotion. It is true. Things do seem clearer and brighter when you are faced with living out a possibly limited time.

I often wonder if dying is a bit like when we moved to New Zealand. We were rushing to do all that we needed to do, clear up, sort, pack, sell the house, make freight and travel arrangements, close down our lives in one place. It was a mad dash, with the final conveyancing of the house only completed four hours before our flight from Heathrow. Then we were airborne. And when we arrived, life was to be very different. Supposedly, I was going home though it felt less and less like it. In fact, instead of being proud to be a New Zealander, as I had been all my expatriate years, I was now ashamed - and this was mainly from the way that competent and educated foreigners are treated here. The tall poppy syndrome is alive and well.

Hopefully dying will not lead to something worse. I cannot

tell. But the analogy is there of the journey to a different place a different life. And there will no doubt be a short period of transition after the struggle to leave.

But I digress - just as the trip to England was a digression. The only trouble was that while we were there I was unable to keep up my good diet because we mainly had to eat at fast food places. Also the cost of supplements was prohibitive as our NZ dollars didn't go far enough. I ran out of Vitamin C which I had been taking in fairly good doses. I have since read that it can be dangerous if this happens as the body rebounds. Prior to this, I had had another period with this problem. The great scare of the Pan Pharmaceuticals scandal in Australia had meant that so many supplements were withdrawn and it became impossible to get what I needed. Again, I had dropped right back on my dosage and had even gone longish periods without. I had not been long back from England when I started having problems. Brian had injured his back lifting a suitcase of books - we always buy books and there is such a wealth to choose from good second hand books in Britain. I had to drive him everywhere and was under quite a strain. I tried to meditate and carry on my regime but it was increasingly difficult. I tried a couple of trial intravenous Vitamin C drips but there was a problem with my insignificant veins and it was so slow. Vitamin C is very corrosive and great care has to be taken with the veins. It stings viciously if it penetrates to the tissues. I was becoming quite disheartened.

Our old stray cat, Silver, became ill just after we got back. He was listless and stinking. I took him to the vet and it was his kidneys - not unexpectedly, though. He had been run over - twice - and this probably damaged them. After a week, just when I thought he might be getting better, he suddenly died. At least I had managed to clean up his fur that day where he had been dribbling badly. Then he lay in the sun among the orchid

plants. He was still there when we got home from Brian's work where I had had to drive him because of his back.

I brought him inside and lay him in front of the fireplace but he seemed to want to come to me. I was trying to make dinner during the advertisements on a TV programme and I didn't want a stinky cat on me as his breath and dribble were pretty bad. So I just stroked him and talked to him. He just sat there and seemed to enjoy it. We had just sat down to our meal, quite late, when there was a strangled cry and he just toppled over - dead! I suppose it was the best way to go. We left him there for a bit and he just looked asleep. However, next day we had to bury him. All our other pet cemeteries were full - in front of the chapel and in front of our new library - so his was the first grave under the orange tree. Poor Silver! He had used up the last of his nine lives!

Not a good month or so! My GP became concerned and wanted me to go back to the hospital and ask about doing less radical treatment. I didn't have much hope as I had approached them on that before, when the cancer was much smaller, and got no joy. Still, an appointment was made - but with the same radiologist as before, in spite of my specifically asking that I didn't want to see him. I felt there was absolutely no point in a repeat exercise so I cancelled it.

This caused me to have a phone call from somebody in the hospital, virtually saying AYou can't do that. You need to see someone. If there is a personality problem, perhaps we can find someone else. There are a couple of others in the department.@

"OK" I reluctantly agreed, and set an appointment for February, feeling I would work on getting myself back on track in the meantime.

I had been consulting a homeopath for the past few months and

when I mentioned to her about the increased bleeding and problems, she wanted me to try and see someone who had trained her in Neurolink practice. She said he was very good, an osteopath who had developed this method and had good success with cancer patients. She said it was really hard to get an appointment with him but I just might get a cancellation. I was already late for my Qi Gong appointment over in Mt. Roskill as Jackie had phoned me just as I was about to leave the house, but I decided to make a quick phone call to Neurolink before I went. I was given a time in early February.

On the way to my appointment, I started thinking about the cost of the treatments. Cancer was by this stage starting to cost us a lot and we were really dipping into savings. Brian's job is by no means secure as he has his own consultancy business but it is hard to get work in his specialised field. I decided to cancel it when I got home. I had barely walked in the door when the phone rang. It was the receptionist from Neurolink, saying they had a cancellation the next afternoon and could I manage it. As I have used coincidence all the way through the latter portion of my life, and certainly in relation to my cancer, I knew that I should take it and never mind the cost. I am really glad I did. I started to improve.

It was a difficult Christmas, really. I wondered if it would be my last. I got Brian a big candle for him to burn to remember me. I was that sure I was going to die.

My daughter was due to come over from England in early February and we were going to have a girls' week away. I was worrying about how I was going to tell my two daughters that I didn't think I was going to make it. I couldn't talk to them about it on the phone. In any case, it was not a good time to talk to either of them. Nicki was trying to get her thesis finished for her Master's degree before she came to New Zealand and then she had Christmas itself away in Istanbul. Miranda owns a

cattery and Christmas is a frantic time for her - I just couldn't burden her with anything else. I decided to leave it until we were all together physically.

11th January 2004 11.31am

Pain again - shooting up backside and down left leg. Just generally unwell and no energy to do anything. It makes me think of dying and I don't want to. I'm not afraid of dying - just irritated that there is so much I want to do and no time to do it. Also, I look around and see the chaos. I don't have the energy to sort it out though I feel I must because Brian certainly hasn't got the time. And if I go, he won't have the heart either. I am very much aware that I do nothing now but fight my cancer - and the damn thing seems to be getting the better of me.

I feel confidence after a visit to an alternative therapist but it is fairly shortlived. I felt great when I saw Ric yesterday but I should have let him examine me as the pain is not comfortable there now - and it is lower down in the part of the bowel he reckons he can see.

Has the cancer spread from the back of the cervix through the bowel? That would be terrible and make for bad symptoms. I just don't know. I can do nothing but carry on as best I can, trying the things I come across. I must find the notes on the Australian bloke with his theories on phosphorous. I have lost those and also the things on the Kelley diet/programme. Everything I need, I seem to lose.

The weather is wonderful - perfect with no clouds and the cicadas are singing away. Is this my

last summer? I hope not. I will endeavour to make it not, as well. But it is a terrible strain, living with this threat hanging over me, just waiting and not knowing. I'll take the ironing outside under the shade of the trees and then I can be near Brian while he works on his website. The trouble is that I don't really feel much like standing. I am tired. I just want to sleep really. Please, Ra, help me to overcome this. I need so much to be able to pull my weight in our work. I cannot do it like this.

12.12 - Just finished first batch of ironing. It is lovely and cool under the trees and I can be company for Brian and vice versa. I hate not telling him I am not well. But he is getting somewhere with the web site and I hate to worry him. I will have a long meditate in the pool after lunch. I was trying to combine it with the ironing but it doesn't work. I am worried. But I am determined I will be OK.

But during January, I started to really pick up. The bleeding eased and I started to feel so much stronger. Maybe I wouldn't have to give the girls that news, after all.

My appointment at the hospital was suddenly changed with no warning - and to make things worse, it was now just at the time my daughter's flight was arriving from England! Still, I had to keep the appointment. It was important. So I arranged for her sister to pick her up and take her to her place.

I was scared and also irritated. I nearly walked out of the appointment, especially when the radiologist then said he couldn't take on my case because he didn't deal with the cervix - so why had I been sent to him then? He didn't want to do another MRI and indicated that it was not cost-effective to continue monitoring me if I wasn't going to have treatment. I

don't see why not. I am actually costing the health service much less than if I had their treatment and it is costing me a whole lot more. I am entitled to the treatment and follow-up, so why should I not be entitled to just the follow-up? The suggestion was that I wrote to the Department and expressed my concerns. However, in the end, he said he would consult his colleagues and see if I could have another MRI to see just what was going on. Fair enough!

Interestingly, this doctor was the first one who had properly heard what I had said. He wrote an excellent letter to my GP, bringing out all my points of concern. Usually they are just glossed over.

We'll see what happens with the MRI! Things are looking more and more bleak.

The MRI was a real shock. The tumour had now increased by a factor of 3.4 in 10 months. Things were looking even bleaker. I had had the results sent to my GP. I was OK at first but then the shock set in and they would not let me drive half an hour home without a cup of tea inside me. The nurse was wonderful as I talked over my fears.

Now came my first appointment with yet another radiologist. The explanation was more thorough and he did answer all my questions. But he could not satisfactorily answer the one of whether, if I am in the 45% who do not make it, would I be worse off than I am now. I suspect I would because my tissue and immune system would have been destroyed.

All the way through, I have been acutely aware of the poem which my children's father used to read to them from Hilaire Beloc's *Cautionary Tales for Young Children* about Jim, who let go of Nanny's Hand and got Eaten by a Lion. It goes something like:

*Now just imagine how it feels
When first your toes and then your heels
And then by gradual degrees
His feet and ankles, shins and knees
Were slowly eaten bit by bit
No wonder Jim detested it....
....The Lion, having reached the head
The miserable boy was dead.*

I haven't been able to find a copy of it since. But it kept coming to mind in relation to cancer.

We were sent a copy of C by John Diamond who, like me, was given an original 90% chance and within about a year or so was dead, unable to speak or eat as he had his tongue cut out because of the cancer. What a way to go? He staunchly defended the treatment he had had, but in the end, it became obvious that he wished he hadn't taken that route. He talked of the principle of gradual disclosure. I could see this in action every time I went near the hospital.

Anyway, I had reasonable confidence in this oncologist and actually signed the paper agreeing to treatment as he said that way he could put me on the list. I was reasonably happy, although apprehensive, until I asked him if I could have a copy of the signed paper. "We're not allowed to photocopy those" came the reply. The System again! Where else can you sign away your life, literally, and not get a copy of the paper? All his good work had been undone in those few words. I could see that if I submitted to treatment, I would be trapped in the system. I was already feeling as if I were in a cage with bars like a lion's cage - strange link to the above poem. They would let me out for a treatment on their terms and then lock me back in again.

On the way out of the clinic, we called at Reception where they were supposed to have left some MRI films for collection.

They have put everything on computers now, with the new hospital, and patients can have the old films. "Sorry! We can't find them. The last time they were seen was September last year." Great! I knew they couldn't find them the previous March when I had had an MRI and they had nothing to compare it with. Again, this did not give me any confidence in the hospital system.

There was the most magnificent sunset way beyond the hospital as we left. One of the clouds was shaped like a huge falcon's wing. For me, this was symbolic of God and gave me the confidence to reject the treatment and to trust - whatever may be the outcome for me in this world.

Now What?



2nd April 2004

Thoughts on my cancer - A Note to My Doctor

It is strange. I feel almost emotionless. If there is any emotion, it is of a kind of exhilaration. Only, in between, I feel one of my states coming on, my muscles going into involuntary spasm and I have to fight hard to divert it.

I can't understand my feelings. I do feel it will be all right. Maybe I'm wrong. It doesn't look too promising at the moment and I am aware in my tissues that there is a problem.

One bit of me just wants to give up as I'm tired of fighting - not just the cancer, but what feels like the whole world. I'm sick of the isolation and the aloneness. I just feels all too much. However, if I do that, Brian would be left alone and he wouldn't survive. All his work would be wasted as he cannot do it all on his own. I think he would just die.

Another bit of me is fighting - and fighting hard. I am trying to understand the physiology of the processes going on in my body, trying to visualise

what is happening and how I can best act. I want to say "It won't get me!"

However, logically, it will. I have fought so hard to this point and it all seems for nothing. My cancer is a drain on us financially and in time and energy. It has made us stronger in our marriage but it is taking its toll. Brian needs to concentrate all his energy on trying to get our work out before we both die and take it with us - perhaps that won't matter as it will be too late for it to do any good, anyway. I need to concentrate all my energy on getting well and on getting him well. And I am so tired.

And I get resentful of Brian devoting all his time to his work. However, his paid work has been very busy this month (which is a good thing, financially). This has meant he has been working about an 18 hour day to fit in the other work too and I have hardly seen him. Even now, I really need to talk but I can't - partly because he is just so tired when he gets in and then we have a meal about 9.30 which is really too late for me, and partly because he seems very quiet about it all.

I certainly have less energy than I did. I hardly go into the garden now. And the summer was so terrible that I hardly swam after January either. I need the water to be warmer now as I chill so easily and that uses my energy up. I had been full of enthusiasm when I thought we could get the section next door and I could keep a goat and chooks. That would have given me something to aim for. But when that fell through, I just lost heart and have never got back into the garden since. I know it would have been just another thing I had to do, but it would have

been therapeutic. In some ways, though, as I have lost energy and drive, it is perhaps a good thing we didn't have that additional burden and expense.

But will I have another summer? I don't know. I hate to think that I might not. I love all the seasons. I actually love life, unlike Brian who has just about given up. I hate to see him dying before me. But he keeps picking himself up and driving onwards. But how much longer can he do that? And now he feels that nothing at all is working, not even my cancer treatments. He struggles with faith in alternative treatments anyway. It goes against his scientific training. He had started to accept things - but now this.....

What I am most afraid of

1. Being a nuisance to anyone. It really stresses me if my drip takes too long or I get into one of my states so that it is a bother to your staff. I suppose I fear this above all. I am afraid that it will be too much bother and I will be totally rejected. I know you will not stop me being a patient, but the rejection can be subtle so that I feel unwanted. (This makes me cry as I type it. It is so really deep in me - such a deep fear)

2. Being a burden on Brian or not being fit enough to help him as I need to. It is bad enough at the moment that I have to spend so much time just fighting the cancer and with less energy, just when he needs me to

have more energy. I just do the best I can.

3. I am not afraid of dying. I don't want to as I am not ready yet. It is such a waste of all I want and need to do. However, I do fear the manner of my going, if it is long and drawn out or particularly nasty. I am reasonably able to bear physical pain. But I have guilt all tied up with this cancer and the pain from that is pretty tough to bear.

4. Let my dying be quick - please - if it must be at all. But not yet.....

The things I am most proud of

1. I have made great progress with getting my emotional problems sorted. I know I still disappear from time to time, but it is getting better. I struggle for control and it is hard. But I think I am gradually doing it. Maybe I will need that ability to completely detach if things get really bad.

2. I am proud of the inner strength I have found since I found out about my cancer. I have learnt so much. I just wish I could pass it on to others. The aloneness is so bad.

3. I have much more equilibrium than before. I feel a calmness and a balance which I have never known.

4. I am generally healthier than I have ever been, apart from this cancer which is not really affecting me much yet.

Other things

1. There is such an aloneness. I am nobody and nobody cares really. My children are concerned now and have offered to help. However, my parents don't express much. Even though my mother now says she thinks the way I am treating my cancer is best, I heard her make such disparaging remarks about others who have tried alternatives. Her comment when she first heard about my cancer was "Cancer is such a killer - financially!!"

Our time here has been the most unhappy of our whole lives. There is nothing here to live for. We are surrounded by people who have little intellect, who hate thinking. There is no job worth having that gives any sort of satisfaction. There is nowhere to go. We are trapped - utterly trapped in a soulless country. And so alone! And so mocked and ignored. Is it worth continuing? The tragedy of it is that my parents were the worst - and they started it - though, strangely, they seem much better now. So I have no sense of family now. I am lost and alone.

2. Point 1 seemed to go on. The emotional problems hurt me far more than the cancer. The cancer is just an irritation, an extra burden - maybe one that will kill me, if God so wills - but the real pain comes from my feelings and my isolation.

3. The isolation is even worse as the hospital will wipe their hands of me. I won't even get the follow-up that any other cancer patient would get - just because I won't do it their way. But I can't!!! It would kill me as surely as if I jumped off Grafton Bridge. That would just be a quicker way to go. But I feel so rejected and isolated because of their lack of support in a way I need. I don't have the knowledge. I am trying to find out what I can. But I need to be able to ask questions, to have things explained. That is not possible. "Just shut up, do as we say and lie under this machine so we can fry you. We might do it competently - we might not". Great! I can't even find anyone who has any interest in what I am trying to do, who can wonder and question the little things I notice and try to look at scientifically. It is the little things that are the key and I don't understand them all well enough - but nobody will listen and help. And I can't even find an oncologist privately, even if I could afford exorbitant fees for them to learn from me.

4. Once again, things are much worse than I had steeled myself for. At every turn it is the same. Each time I get results, they are the worst possible. It was the same with the cone biopsy and the last MRI. So I don't have any faith at all that things would be better for radiation. I would totally lose control over my treatment. And then the worry is that if I lost control by "spacing out" or whatever I do, then I would not be able to do anything to prevent what I felt was wrong. I would be powerless, paralysed, just as I am when in that state. I would know what was happening but be unable to react, feel an emotion, speak, stop what was happening. I can't do it - I just can't!! Please help me. I am sobbing and trying to regain control. It is just all too much.

You asked me to put down my thoughts on my cancer. It seems that my emotional state is where the worst problem lies. And I can't get any help with that. Some sort of moving forward in our work would help. It is as though God is powerless. And that is a terrifying thought. We have always been helped up until now. And now it is as though I have been abandoned even by God.

I know that I will only live if God intends it. I don't know whether He has allowed things to get worse because He intends that I finish my struggle on earth. It seems that what we are trying to do is futile. Maybe we are both to die in the quite near future. And then what will happen will happen. I think it is

already too late. Nobody wants to look carefully at what we say. It makes most people uncomfortable - even you. You didn't read it thoroughly and you won't talk with me about it. Yet that would be one of the most helpful things you could do for me, to help me.

I will continue struggling. I might as well end my life struggling as that is how it has been lived. I have always gone against the flow but it does cause conflict for me. "Everyone marching out of step but little Jenny" my father would say.

It has been hard to write. I am now in tears. It is 9.15 and Brian hasn't even left work yet. That means we will be eating after 10 pm again. I am feeling very alone. I need to be able to talk to someone independent. I miss being able to talk to Simon as he did understand what was going on underneath. However, he has gone on to a new life - and that's fine. But it has left a gap. You don't have time as you are always so busy with the practice and the school, etc. It must be very satisfying. I am often envious of that - that you can have satisfaction from your work, respect, status in the community, and manage to help people. We have none of that. We are treated with contempt or ridicule. We often help people for no reward, but they always take no notice or turn it back on us. They don't respect what they don't pay for. But we can't charge. We often spend hours trying to help someone, without even thanks.

But we are of no consequence. We have no position in society. We are unimportant. And therefore what we have to say has no consequence or importance. That is the way of the world now.

Even a one-time friend of mine who went to a more comfortable way of looking at things, finally sent an email saying it seemed we were right about Mary Magdalen after she had watched a TV programme. She hadn't even bothered to look at our site until she remembered the draft book we had

given her to read and now it seemed to be corroborated by someone in authority. She's too busy in her own life - too busy even to lift a phone and see how I am with my cancer. It is not the first time. She has treated me like that all through the relationship. I was always there, ready to listen to her. She has no time. Her time is important - Quote "Some of us have to earn a living", with the distinct insinuation that we don't.

There is no way we can get anywhere. The censorship of our site is the final straw. We are being watched. The world is a terrible place. There is no freedom. It is quite scary in some ways. However, I have always felt we could be killed, right from that night in the police station in Chelsea when they arrested us and took Miranda away and then dumped us back outside the flat at dawn, still in my night clothes. Yet we had done nothing wrong then and have done nothing wrong now except speak out. But that is the most dangerous thing you can do in this cruelly controlled and fettered world.

There is so much pain, so much anguish, such a burden of things that I need to express. More than anything I need to be understood, really understood - to have you listen and not joke. I am going to explode. How can my cancer ever get well while I am so burdened?

Yet, I do feel a peace when I meditate. But am I kidding myself? Is everything a lie? If my cancer had shown some sign of improving I would have had more hope for our work. But it is worse. And the censorship is worse. And the hopelessness is worse. What is the point of continuing?

Brian has just phoned at 9.35 to say he is on the way home. Back for probably 10.15 and then some homemade tomato and celery soup - I suppose that at least is positive. It is almost impossible for me to have a routine and to keep my equilibrium like this. But I can say nothing. He will just bite my head off.

What he is trying to do is more important than me. He is under such strain.

As for the cancer and what I can do.....I don't know. I can only continue as I am and trust that I am not kidding myself that it is actually getting better and just hasn't had time to show up yet on an MRI. But all the time there is the dull pain. The discharge has almost cleared up completely. I can't understand that if things are worse. Surely I should be having bleeding and discharge???? I used to feel as if there was less distension. But since I got the MRI results, it feels worse. Is that just imagination? I am aware of a low pain just below the bladder and a tingling in the vagina all the time. Could this be as Kelley mentioned, just an inflammatory reaction before improving? I don't know. Maybe I'm only admitting to the pain, now I know what it could be - cancer in the bladder as well. It is just above the pubic bone and there all the time. I used to put it down to wind pain.

I have faith, and it seems it is misplaced. I see the signs and I follow them. But it is worse. I just don't know any more.

I am loath to spend vast sums of money on something else. I had felt the Vitamin C treatment was working. I did feel better for it. But is it? Is it making things worse? I don't know. And there is no way I can find out. I think I am right. I use my pendulum. I seem to be shown the way. But things seem worse. Is the calcium/phosphorus balance wrong? Is that harming me? I don't know. And nor do you. How can I check the pH balance? I just have to continue as I feel is right. But am I clutching at straws? Or am I just remaining steadfast? I don't know. Is it actually too early to tell if there really is any improvement? But is that just kidding myself? I don't know. Only God knows. And God isn't giving me any answers.

And "they" will certainly not support me. The trip to the hospital is going to be so destructive to me. They will put pressure on me or tell me it is terminal and there is nothing

more they could do and it is all my fault for not listening to them. So I had better take just this last chance they are offering before they toss me in the scrap bucket. But I can't. But was I wrong? I don't know. Or would I now be dead? I think that is more likely. And I certainly wouldn't be as fit as I am now.

Nicki said to me when I phoned her in Paris last night that, apart from this thing inside me that could kill me, I am fitter than she has ever known me and look great. I suppose that is something. But it seems to be getting worse - and fast. That is what I can't cope with. And I thought it was getting better - that's the really hard thing. So where does that leave the rest of my life? Is the cancer growing so rapidly that it is going to overwhelm me in a few months? I don't have time to get everything in order. We live in chaos from day to day. I just can't get everything sorted. And Brian certainly can't.

I suppose I really should think what I should do about the cancer. I just can't think. I will, I suppose, just carry on as I am and trust. It is either that or give up entirely. I cannot find anything out accurately. The lack of science and willingness to look at something different is frightening. I cannot be part of it.

Please help me to sort all this out. It is really important. I am trying to be calm, balanced, positive. But things don't look promising, either for my life or my death. The mental and emotional pain is so bad. And now it seems I have the physical pain to look forward to as well.

But I won't give up yet. I will fight. But I really do need help. I feel so alone, without any of the cancer supports. There are probably only my husband and my daughters who really care at all what happens. The only friends I have are met through medical channels and so they can never be friends. They are just paid to be there and try to help. But I cannot treat them as friends. It is so hard. It is really horrible when you have to pay to have human contact. I have tried to join so many things and

each one has been so unfriendly and so I have left. I hate the way I am becoming here. I used to give way to people when driving, giving a friendly smile. Now I find myself becoming aggressive and not giving way. And I hate it. Pain! That's all I feel - pain - and not from the cancer.

3rd April

It's just before 6 am and I have been awake sobbing quietly since I woke at 4 am after only 3 hours' sleep. I lay listening to Brian sleeping beside me, aching for him. I want to cuddle up to him and be comforted but he needs his rest. I am so tired now but if I don't write this now, I will not have recorded how I feel. A storm is brewing. There were a few drops of rain and a rumble of thunder. I could see the trees swaying outside, silhouetted against the approaching dawn sky. It reminds me of the night I got my first diagnosis when I wrote for several hours while watching the trees outside against the night sky.

Maybe it's just sinking in - the enormity of it.

Brian just called out and asked if I was still typing? Again? He had roused and heard the keyboard. So I went back to bed and sobbed in his arms.

Ric, please try to understand what is going on inside me - the emotional stuff. That is what is doing the damage.

How about Chemo?



There was just one more treatment to check out and that was Chemotherapy - the 'icing on the cake' as I had been told by every single person! Apparently, it would give a 5-10% greater chance of survival - but at what cost to my immune system?

28th April 2004

Yesterday morning I went to see the medical oncologists and was not at all impressed. They were just SO positive and unrealistic. Any feelings of confidence I might have been feeling from the radiologist were negated. And they immediately made the same mistake - refused to let me have a copy of a letter which was sent to me but had not yet arrived (for medico-legal reasons!!!). I nearly exploded. And then they turn round and say to trust them!! How can I?

Interestingly, a book by Bernie Siegel, that I have just been led to in a strange way, talks about how it is important not to negate a patient's strongly held views about what can help them. The oncologist yesterday just sat on the bed swinging her legs and said that she had seen it all - Mexican cancer clinics, caffeine enemas, diets, supplements, etc, etc. and

all had failed and led to only death. This is a singularly unhelpful approach. I need support, not shooting down.

Yesterday afternoon, my GP set up my Vitamin C drip and then just sat gently and let me talk. He tried to work out a compromise and wondered about using a combination of treatments. However, the hospital just will not countenance it. With them, it is all or nothing - do it our way or push off.

I have already tried to ask about using things like Vitamin C and they just rubbish it and say there is no evidence. I myself have read medical studies on this - so it is just lies.

So how can I trust them, yet again?

Last night, I meditated for an hour before going to sleep. I had been really stressed and exhausted after spending all morning at the hospital for what was supposed to be a 45 minute appointment. I had left home at 9.15 and got back at 1.45. And I was so stressed. I fear that will be what it would be like for 7 weeks as it is even more stressful trying to get into Auckland Hospital and park.

However, a warm bath and a coffee enema in the evening after my Vitamin C treatment and an hour's sleep at the doctor's helped me to relax and unwind. And then I meditated. I kept having to push away thoughts of the hospital. And every time one intruded, I could feel the chemicals from it swirl through my system. Then I would pull myself together again and calm down. Then I would find myself tensing and another thought intruding, memories of the day. And again there would be a sudden release of hormones.

That is the worst thing possible for me. In between I was calm and happy.

This morning, I meditated for an hour and a half, this time changing my concentration. Again, I could feel the surging of chemicals through me if I allowed any thoughts of the hospital to intrude. It is so harmful to me. I try to remain calm but it uses a lot of energy to keep that way when faced with all this negativity - or positivity as they would call it. I hate being talked down to, made to feel as if I am wasting my time. Apparently, according to the oncologist, my case is a 'no-brainer'. They even promised me 'eternal life' as I would be completely cured! The new priestess? I was really insulted at that.

Whenever I feel supported in what I feel is right for me and my body and my philosophy of life, I feel calm, and even joyful, ready to face whatever might happen, whether it is getting better, holding things as they are, or even dying. Not that I want to die, but I have to face that it is a possible outcome. It is also a possible - and to me probable - outcome of following their way.

The statistics give only a 50% chance - and that is in a first world country, not here where it is admitted results are worse than Australia and certainly worse than America or Britain. Now, if I am going against what feels right and have no trust at all in the system, then how is that possibly going to be successful? It is all very well saying I just have to trust. I have in the past, and every time I have been let down. This is a life or death matter and once I have trusted and it has gone wrong, there is no going back. And she admitted yesterday it might give me two or three

years more before the cancer starts to trouble me. I am not that desperate to live!

I need support. I cannot do this alone very easily. I have a very strong faith in God and know that if I am meant to live, I will and if it is my time to go, then I won't. But that is not for me to say. I am trying to do everything possible to keep my body functioning as well as is possible, to give it the best chance to get better. I am trying to keep my mind as strong as I can as this is my most powerful tool. And I find it so difficult to accept the medical profession rubbishing all my efforts and telling me I will die if I don't do it their way - which is a way which goes against building up the body but poisons it instead. Yes, I know it has been shown to help in many circumstances. But I have only a 50/50 chance - and that if I can trust them.

Without trusting them, it is a non-starter. But each time I go to see them, hoping to trust, I am let down yet again and again and again. I trust my GP because he is willing to work with me, to support my efforts, to feel my pain and anxiety and try to help on that level. That sort of support, right to the end if that is necessary, is what will get me through this traumatic time in my life.

I have gained much by having cancer and having to develop the strength to change my life and attitudes. I do not want to give up all that and be hauled back into the system where I feel trapped. Every time I think of it, it is as though I am in a cage with bars about 6 inches apart. I am let out for a poisoning and then put back in the cage. And every time I feel the hope ebbing away. I am isolated and

alone, frightened and trapped. And I cannot escape. I am far more afraid of the system than of the cancer. When I said that yesterday, the young oncology registrar was so bothered. She said her heart was racing and she just couldn't cope with that concept. But it is true. Their first loyalty is to the system, not to the patient. They must look out for their medico-legal liabilities before meeting the patient's needs.

But when I take my supplements, do my meditation and Qi Gong exercises, walk in the garden in my bare feet with the leaves rustling, listen to the birds, feel the touch of the sunshine on me, grow my vegetables, prepare foods which are good for me and my husband, love life, I feel a calm and a joy and almost an exhilaration. I can do it. I know I can. And I will give it my best effort. I am at peace with myself. And whatever the future brings, I can cope with it. If it is not to be that I get well again, well so be it. But I will know I have not been pushed into something that feels wrong.

It is the fact that they are pushing me all the time, pushing, pushing, don't let her get away, don't let her change her mind, good girl for taking a sensible choice, etc, etc.....That scares hell out of me. My GP is talking to me about some radiotherapy and helping me with other things to reduce the side effects. But once I am under the system, I no longer really have that choice. It is all or nothing.

And that is how they have been right from the start - I couldn't have a simple hysterectomy instead of taking all the lymph nodes; I couldn't have internal radiation at a time when it probably would have been

effective but had to have the full whack. And so it goes on. And now I have to have the full standard treatment.

I am still discussing things with my GP and he is bringing me some stuff to read when I visit next week. I trust him and he is not pushing me at all. He agrees we have to do something to shake up the cancer. It has been held fairly well at first by all that I have been doing but I need to do something more now. What that is is unclear.

I am struggling with making this decision. I am scared. But I do not want to be pushed into something as a last-ditch thing to save my life. That would be utterly wrong for me and would lead to a complete psychological breakdown, destroying all the health I have gained in this area over the years as I have got stronger.

I want to feel at peace with my decision so that I can put my fullest effort into whatever I decide. And pushing me is the last way to make me feel that peace and trust. I need to feel safe and in control with my decision. Only then will I be able to heal.

These last few weeks has been difficult and I can feel the tumour is slightly bigger - only because I am unable to devote my time to healing and because I am so distressed every time I have anything to do with the hospital. The colposcopies I used to have were so helpful to me and I felt relaxed and sharing a relationship with the surgeon. I trusted him. When that was suddenly denied to me and he didn't even respond to my letter, I was devastated and felt the whole system had let me down so badly. The

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greatest deterioration has happened since then as I have felt lost and alone with no support, just trying to force me to go against what feels right inside.

Peace and Acceptance



Perhaps the most useful thing that the Oncologist has done is to refer me to a psychiatrist. The reasoning behind this was that I could be given sedatives to enable me to get over my fears of Auckland Hospital and therefore manage to get through treatment. What has happened, as there are no psychiatric appointments until June, is to see a final year psychologist. As it happens, the subject matter of her thesis is what cancer means to different patients. Very appropriate. However, I have six sessions with her and am working really hard to make the most of them.

I am discovering how to change my thinking patterns, to let things wash over me. This is an essential skill if I am going to get well. I can see the way I have reacted in the past.

I genuinely do feel peace now and an acceptance of my life and of whatever is to come. Hopefully, this cancer will eventually go, or at least not get any worse. But if not, I have gained such a lot from this cancer journey. I have an appreciation of life and a real love of it. Yes, I do have fear, especially when I feel pain or the cancer seems worse. But I am working on ways to ease that.

I smile and am happy. Life is good. But just how long will it last? That is not for me to know.

The other day, driving over the hills to the doctor's, there was a brilliant glow behind the huge clouds. It was right at the top and the light started to spread all around. I appreciate these little things, these signs that God is indeed in the world.

It is now 6.45 am and I have worked straight through for 21 hours to finish this book. (I was prompted to put all my cancer material together - the notes I had written when in an emotional state, the letters to those who were helping me - as a result of a literary competition The Ashton Wylie Award for an unpublished manuscript in the Mind, Body, Spirit genre. The manuscript was due in on 31st May 2004 by 5 pm and I only decided to do this a few days before. However, I found it a very therapeutic exercise and perhaps my cancer can have a purpose. Unfortunately, because of a mix-up, my manuscript was never judged.)

The first birds have started their dawn chorus in the grove of trees at the bottom of the garden. I can just see the silhouettes now as the sky starts to lighten.

Yes. It is good to be alive!

And Into the Future.....



So, here I am. I have learnt a lot. I have wept, got angry, argued with the doctors, been torn apart emotionally, been prodded and poked and examined. But I am still here. And I intend to be for some time yet - until my work is finished and then I can go gently, with a sense of closure.

Relationships have improved with my husband, my parents and my two daughters. This focus has brought us much closer together. Through that I will heal, and hopefully they will be able to as well. There has been much pain and sorrow. However, when the loss of one member of a family is a probability, it does change the priorities.

I am stronger emotionally and in better health physically than I have ever been. And my spirit and resolve are strong. So, we'll see. I am aware it is a matter of keeping vigilant at all times.

I have a calmness and a peace - in fact a real joy. That is a totally unexpected bonus. I never thought I could feel such warmth of emotion flooding through me.

So that is what my future holds, however long or short it may be. I am truly healed. All it needs now is for my immune system to wake up and gently push the cancer out of me. I visualise white balloons floating upwards, each with a cancer cell clinging to the string. They float upwards, upwards, into the billowing 'Constable' clouds..... And I am healed!

The psychologist suggested I write a letter to my cancer, telling it how I felt. This was the result. It was really quite a cathartic process.

My letter to my cancer

8th June 2004

Hello Cancer

I want to say thank you to you, my own unique cancer, for being with me all this time and giving me the opportunity to change and grow and learn. You have been a great teacher. I am now stronger than I have ever been and also healthier as I have had to learn how to make the most of my life, of my food and of the capabilities of my body. And my mind is also so much stronger. There is nothing like a risk to one's life to focus the mind on the important things.

Anyway, my cancer, I have caressed your shape with my mind, gently helping you to get smaller so that you don't get out of hand and overwhelm me. There wouldn't be any use in doing that, would there? That would mean that you wouldn't have a home. That seems a bit stupid. You have been with me for a long time now, nestling deep within. I have looked at your picture on scans and photographs. I can feel you within my body. You are part of me, if a little renegade.

But you know, I don't really think you need to stay any longer. You have helped me so much to understand and for that I am grateful. However, now I can free you. You no longer have to remain trapped

My Cancer Journey

within me. You are free to go - back to where you came from - with my blessing and thanks.

Perhaps you would like to fall out of me so I can keep you in a bottle and we can be friends. Or perhaps you would like to gradually dissolve and be wafted along my bloodstream until you can safely go out of my body. It doesn't matter. You can choose.

I will miss you in some ways. You have given a purpose to my life for the past four years as I have tried to coexist with you. I have tried to be gentle towards you as you are a part of me. In fact, you have taught me about gentleness. No longer do I need to hurt myself or agonise in my mind. You have taken me by the hand and led me gently in the right direction for healing of my past.

You have helped me to come to terms with life. You have helped bring Brian and me closer together. And now I need that closeness more than ever as his life seems to be in doubt. If this mass behind his eye is a tumour, I pray that he can come to a similar understanding and peace as I have with you. But it will be a hard road for him. This closeness, though, is a warming experience for me.

And I have had to be honest - both with myself and with him. This means we have had to talk about difficult things. This we have managed to do. So I thank you for that and for this closeness and the strength you have allowed me to develop to face what I may have to face with him now.

At first I was angry and couldn't understand why you should be in me. Then it all became clear. I understand why you were sent to me. I understand why you have grown bigger. But now is the time to

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get smaller again. I will caress you and help you with that.

Once I came to terms with you, then I saw how you have freed me. I am going forward now and you must not hold me back. I am no longer afraid of you. There is now a peace in my mind and a peace in my heart. I can feel myself soaring upward in joy and exhilaration as I grow ever stronger.

We have learnt to live together in harmony. Now we must go our own separate ways. I no longer need your help. But I will never forget you and what you have done for me. So, goodbye my cancer. Farewell and thank you. You have given me life.

With fondest wishes,

Jenny

It's Time to Go Now



Gently I said to my cancer
Lurking deep
Within my womanhood
Thank you for being with me
But now you may go

I have learnt from you
How to live
To love and laugh is good
The matter of my life
I have come to know

But my cancer said to me
I do not want
To leave this warm and nurturing place
Where tissues make me welcome
Do not recognise my form

Be gone, I told my cancer
You now must go
Full health must fill the space
Where you have rested long
Before the coming storm

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The wind of change is blowing
Deep within
Washing clean my body and my soul
There is no room for you
I am completely whole!

1st and 8th June 2004

A CANCER JOURNEY

Part II

FAITH BECOMES EVER MORE
IMPORTANT

‘Til Death Us Do Part



And now to Phase 2 of the battle....

Since the original writing of this book, things have moved apace - and in a downward spiral. Brian had trouble with his left eye and a few weeks later, in fact the week after we had got our books into the competition, the GP noticed it was pushed right forward. Here followed an urgent round of scans and specialists' visits. At first it had just been considered 'thyroid eye' as he had had thyroiditis a few years back but it was now in remission. However, a routine CT scan indicated a large mass behind the eye.

We had had the results sent to our GP so we could visit him on the Saturday morning as it was Queen's Birthday weekend which meant that everything was closed on Monday. Ric read the report out. There is a mass there of..... by..... Brian said "Millimetres?" "No - it's centimetres." That was enormous - almost half the size of my tumour! What now? Was it growing fast? Would he lose his eye? Is it cancer? Is it just the tip of the iceberg, as he has felt very unwell for some time? So many questions, so many worries. And no answers.

So, it was off to the internet to try to find out what we could about orbital tumours. There is not a lot written but there was an outside chance it could be benign. It seemed to have

come up very suddenly and this was of concern. However, Brian did comment that he had noticed his eye watering since he had started using his new digital camera in April. You see, you have to spend a lot of time squinting into the eyepiece or into the small screen to set all the parameters. You don't have to do this with the old Pentax. Perhaps this had exacerbated the problem by making the eye muscles inflamed and thus showing up the tumour.

It seems an orbital tumour is quite rare - only two or three per year in New Zealand. This meant that we were very limited in finding someone to deal with it, or even to have a second opinion. However, by 'chance', we did find the right person at Ascot Hospital who referred us on to another surgeon as it was so specialised. He said that it could not be removed completely and so the only treatment would be chemo if it was a lymphoma, or radiation, but that would depend on a biopsy which he wanted to do a couple of days later. This is a major procedure, as it is almost impossible to reach. You have to go in through the eyelid and hope you can get a bit of tumour. Apparently, it all looks much the same - just like yellow fat. It all sounded a bit hit and miss.

Brian was on the point of having it biopsied when all the signs then said "Don't touch it!" As always, we go with the signs. The only treatment, as it can't be totally removed is radiation or steroids anyway. And, again, will it exacerbate the situation if a surgical biopsy is done? Will it disturb what could be benign and turn it malignant? In any case, the surgeon was just the middle man. He would then pass Brian on to another branch of medicine. But as Brian was against radiation or chemotherapy, this biopsy would serve no purpose.

It is a doubly worrying situation as now there are two of us struggling. Again, it is in a place in the body which is of vital importance. For Brian, his eyes are everything. He does fine

work and he reads so much information and writes books, so is doing a lot of close work. He is struggling not to lose the vision as any stress inflames the eye muscles and gives him double vision. All the signs seem to show it is inflammatory - but it could well be a lymphoma. So, once again - decisions.

But we persevere. I am having to adapt my cooking even more - and trying to wean Brian off his favourite foods. The steroids mean that he is putting on weight at quite a rate and for someone who has never changed by half a kilo since his teens, unlike me who just has to look at food to put on weight, he finds this distressing. There are so many side effects. All I can do is try to minimise them by diet and lifestyle and reduce inflammation by all natural means at my disposal so that he can be on the minimum dose for as short a time as possible.

But things are sent to try us, I guess. We both feel that we have little time left. But there is so much to be done and only us to do it.

And now my cancer seems worse. Little bits of cancer had been breaking away and I felt "Good - better out than in - that's less for my system to have to process." The bleeding would be short and sudden. But the niggling left hand pain was there almost all the time. Suddenly, more and more broke away and on testing, it was found to be just inflammatory tissue. So where is the cancer? Is it causing more tissue damage and just continuing to grow? But the bleeding would cease almost immediately after I lost the clot.

All this begs the question of where will it end. With both of us sick and everything taking longer and longer because of our tiredness, it seems there is not much longer for either of us.

It all started to get too much and so, as usual, I put my fingers to the keyboard and wrote to the only person I could trust who is supporting me, my GP. For me, this is the most cathartic way of overcoming my worries.

5 pm 10th September 2004

I have to write as I find it impossible to explain things during a visit to the surgery. Brian's vision was really bad when he woke this morning. It was badly double and when he wrote in his notebook, he realised that he had started half way across a page, thinking it was the LHS. He phoned John Bowbyes this morning and he has arranged for him to have an MRI scan this time - booked for Wednesday evening.

Brian feels hopeless and helpless and I just don't know how to help him. The eye is the final straw. It is hard enough for us to cope anyway without this. He just feels it is the end. But what is the point of all we have tried to do for so long? It is like a betrayal of our faith.

Our work is so important. For 18 years, we have done this research. Countless times every day we are shown that the conclusions are correct. But nobody will even look at the evidence. And it is so exhausting keeping track of all the information. But there is definitely something in it all.

Brian is split into several parts as he tries to earn a living in an environment which is singularly unpleasant and unrewarding, where nobody listens to him or does what he suggests, but then they blame him if it is not right. Professionally, he has never felt so low as in NZ. It was the worst thing we ever did to come here. I have watched him dying in front of me for the past 8 years as he has become more and more frustrated and isolated. I find this terrible for me too. I used to be proud to be a New

Zealander and always defended my difference when overseas. Now I just feel shame and guilt that I should have come from a people who have treated him so badly.

We are at rock bottom - socially and professionally isolated and with a very insecure future. We live in an area of poverty and lack of intellect. And we have no place in society, no voice. Remember how I said to you that you are respected, just by virtue of being a doctor. People want your help, even if they don't take it. You will never have the problem of being out of work - usually you have too much. And then you have your position at the school as a School Governor - you have a place in society. Most of our energy goes on our coincidence work. We spend so much time and energy on it but receive no reward. We try to help and guide people but do not receive any payment or feedback. It is so disheartening and there is only so much we can give. Nobody takes any notice. Yet it is worth looking at. It is just that it doesn't sell what people would like. It has a harsh message - but then this is a harsh world. You only glanced at it rather than reading it coherently. OK, you are busy. But then that is what everyone says - it is too difficult; they are too busy. And they don't like the message. We have friends who know Brian well, know his abilities and, in long hours of discussion, can find no other explanation for our conclusions, yet fight desperately to avoid admitting it because they do not like these conclusions. They feel a discomfort that there may really be a orchestrator of these coincidences - that they are not just random chance. So this leaves a question of an orchestrator - a God

who is able to speak through coincidence and who is not amenable to man's manipulations

And then there is the sense of betrayal. We have used guidance all our lives together. Since coming here, it seems to have failed. My cancer and now Brian's are almost a mockery. What is the point of our having all this information and things to get out to the world when now we have even less energy? Yes, there is a strong sense of frustration at our inability to get the message across. However, that is because God gives man free will – and man doesn't like the message so tries to ignore it. The frustration builds to a crescendo and then something wondrous happens – perhaps a significant series of coincidences which are so strong as to take the breath away. Then all faith returns. It is a rocky and difficult path, though. However, it is how we have lived our lives and how we are guided. And nobody said life was meant to be easy! It is actually a test of our worthiness for the next life. That is what our work has shown us. We live in chaos because our home is also our workplace and there is research material all over. And I haven't the energy to sort it all. It takes me all my time just to provide the right food (which is difficult as he is so fussy) and to work out what supplements, etc. Brian spends any 'spare' time trying to draw up webs, struggle with secondhand equipment which keeps not working properly, being frustrated at every turn. He is trying to do the work of at least three people. And I seem less and less help to him.

I wonder about the stress in his life. He has been under considerable strain since being here. And it is getting worse. Yes, we can survive - just. We

can put some by - but that is getting more and more doubtful. We have no pension - but then I don't think either of us will need it. I can see how the stress has affected him. And he is irritable and sad, neither of which endear him to others. He came here, open and with a lot to offer. However, he has been cut down at every turn and made into what he now is. I am just so sad to see it.

This was once my home. Now it is nothing but a prison which is killing us both. And we are utterly trapped. How many able people has this country destroyed? I tried to do a survey on this once, but got no cooperation or help from anyone. Immigrants are too afraid to really say what they think or they will find themselves ostracised.

I don't know what to do. Brian is so tired, exhausted, and doesn't really have the energy to carry on. Will I lose him? He has lost that driving spark that kept him going through so much. Now there seems no future. And his kids don't care, don't contact him. The pain from that has made it all so much worse. Unless he has something to live for, he won't be able to carry on. I am not enough reason for that. His work must succeed. I cannot carry on with that on my own, either, though I would do my best. All my efforts to get well seem futile now, too. We still have got nowhere. It is as if we didn't exist.

Anyway, Ric, sorry to have gone on. I feel a bit low. I also feel almost unreal, as though this is not happening. And I am afraid. Brian is coming to see you last thing Monday night. If that is no good, please change it. He needs to be listened to. That is the most important thing. He needs to be heard and

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understood and accepted. There is so much you don't understand about him.

Meanwhile, I shall just carry on loving him, trying to help him as best I can, supporting him in his down moments, and trying to keep going myself. I am determined to beat my cancer - but I am worried about Brian's resolve. It has all just become far too much now. And who or what can we trust?

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Brian had been on steroids which had helped enormously with the swelling. However, when he tried to come off them, the swelling came back as bad as ever. This had been very depressing and the worst moment came when he realised that he couldn't see properly at all. I can't help him much and I can see that it is worrying him. But it is also an additional burden on me and I am afraid of talking about my problems which makes him feel as if things are even more futile and that there is little life left for either of us. We couldn't get much lower.

We struggle to carry on with our coincidence work. It is soul-destroying. However, we are sure we are right. We are attempting to follow what we feel is our destiny. This may be an alien concept for some. However, our work shows that each has a destiny, if they will but seek it instead of following what seems to give the best short-term gain. Now, with both of us ill, time becomes more of an essence. There is just so much to accomplish and the end seems so close.

But no matter what, we always manage to rise above it. Whenever we are our lowest, something happens to help us keep going. And we have each other. But, for how much longer?

And Now Comes the Pain



14th September 2004

I am so scared. Everything seems to be getting worse and I dare not let on to Brian or my family as that would burden them more. Yet honesty is best. My girls know if I am holding something back from them. Fortunately, they are both preoccupied with their jobs at present. And Brian most certainly knows if I am hiding anything.

The trouble is that constant pain makes me irritable, especially when I am trying to hide it. It also makes me afraid. I have not really had pain before and this new development worries me. Is it the beginning of the end? Will it just get worse and worse to a point where I cannot control it by my relaxation and Qi Gong methods? And the worst thing is that I am less and less able to help Brian while I am feeling like this - but he needs my help more than ever. Talk about 'On the Beach'! A couple of old crocks.....

I can feel a fullness low down when I bend over - a bit like early pregnancy. In fact, when Ric last examined me, he said that I felt about ten and a half weeks pregnant. As that was almost impossible,

then it must be something to do with the tumour. It must be growing a lot faster. And all the time the low dragging pain.....

One of the hardest things for me is having no real follow-up. If I am not going to have the hospital's treatment, then they won't give me the normal monitoring that I would have had if I had had treatment. This seems a little unfair. It is not as if I am doing nothing, which is what they imply. I am fighting really hard and it costs me a lot in financial, physical and emotional terms. I need the testing to gauge my progress. However, they do not see it that way. At least Ric is willing to continue to support me in my endeavours and I find this invaluable. Otherwise I would be completely alone. However, we are both working almost blind. It is not the sort of cancer you can see or which shows any real markers. All we can go on is any discharge or bleeding, as well as my general well-being. It is so difficult.

I had made a little plasticine model of my cervix showing the extent of the tumour and based on what I could feel and what I knew of the size of it from the last MRI. I found this helpful, if a bit alarming to actually see the size of it. But I do need to be able to properly visualise it and then concentrate on making it smaller, dissolving it and letting it be removed from my body.

Ric said I should make one every few weeks to see any changes. I can definitely feel changes and I had hoped it had got smaller. However, on examination he said "I don't think it is any smaller." Damn. But at least he is honest and tries to help me be objective.

So there it is, feeling bigger on examination and also to me subjectively. There is now pain and dragging backache. And there is more bleeding - almost constant. Am I also going to become anaemic too? But then that would be the least of my troubles.

How to remain calm and confident when it all seems to be falling apart? I continue with my meditation and my coffee enemas which do really help the pain. I have had to increase the frequency of these. I am not quite sure why they help the pain - perhaps they shift the pain causing chemicals from the liver when it is stimulated. I remember reading that Ian Gawler found that almost constant coffee enemas were the only thing that helped his pain when he was at his worst.

And the meditation helps me so much too - only it is much harder when everything is so uncomfortable. I listen to my piano tape and feel each note of the music striking a different bit of the tumour, or in the calmer parts, I can feel it stroking and stimulating the good tissue. I cannot let it get me down.

But I am afraid. I have so much to lose. You see, if I had had the orthodox treatment and I had become much worse, then I would have had the support of the hospital. And people would say how sad it was after all the treatment I had gone through that it wasn't successful in my case. However, as I have chosen this course, then if I don't make it, people will just say *Al told you so.*@ There is no guarantee, however, that taking the orthodox route would have been better. I might well have been worse and I could be dead by now.

I should not worry what other people think. But one of the hardest things for me in all of this has been to be able to go against authority in the form of the medical profession. Perhaps one of the reasons I have cancer is because of my inability to stand up for myself and then the frustration of feeling walked over and not listened to, so that my actions have been dictated by others all my life. But it is scary to stand up, especially over something as important as this. Yet, perhaps it is its very importance which makes it imperative that I found the strength to do what I felt deep down was right, in spite of what is considered best by others.

It is spring - almost. Will it be my last? I am so very aware of the subtle daily changes in the garden. The birds are all becoming active and plants are valiantly trying to bud in spite of the cold and the wet. I sniff the air and I can feel it - the coming warmth of summer. The heavy clouds which hang overhead all day do not do much for the way I feel. Their weight pushes down on my pain. I just have to hold on until spring breaks properly.

My vegetable garden is in desperate need of some attention. I have to make the effort to get out and dig it and shift all the compost heap and dig it in. It is not the most comfortable sort of activity for me at present. However, the seasons don't wait, even if this particular spring is a bit slow. If we are going to have fresh vegetables for the summer, I have to act. In a way, though, it is doing something positive, something that looks to the future. I love to watch things grow.

And Lucy is expecting her kittens in a couple of

My Cancer Journey

weeks. I love to help her raise them. There is something so gentle and trusting about little kittens. To watch their daily development is a wonder.

They give me so much pleasure. Sad that Solo was run over. I do want to keep the family line of Glaswegian cats going. We brought one of our cats, Sooty, from England and she was pregnant on arrival. We kept two of her kittens and Lucy has had a new family every year. She is getting older now and if anything happened to her, the line would end. Solo was to have continued it but.....maniac drivers who scream up and down our road, thinking they are so smart making all that noise. So, if Lucy has a girl, I will work on keeping it.

So life goes on - and I relish it.

Another MRI



20th September 2004

Worrying and fretting. Things seem worse. And just when I need support, Ric is going away for a month so there is no support. I find it helpful to go over to the surgery for my weekly Vitamin C drip as I chat to the staff and to Kate, the practice nurse especially. Strange coincidence that she had lived in the very place in Scotland where we had got all the mill end paper to do the special editions of our books. She had even been to our Egyptian exhibition in Edinburgh during the Gold of the Pharaohs exhibition there in 1997 although she didn't remember seeing me there. We did, however, have a girl working for us as we couldn't man the shop full time. Kate is easy to talk to and has experienced much of my own background, living in Africa, etc. I don't feel judged by her in the slightest, even though I know she would have made a different choice for her own treatment if the issue arose.

It will be a relief not to have to go over in some ways as it is a long flog and takes up a whole afternoon a week as I lie there patiently waiting for the drip bag to empty - usually anywhere between

two and three hours, depending on how warm or relaxed I am, whether the vein is good and there is only really one decent one which we are protecting so much. I go in there with my hot water bottle and wheat bags and help myself to the kitchen to save the nurses having to bother. Then I wrap myself up in the blanket and wrap a shawl round my neck. I make sure I have my drink bottle, a book and my Walkman with my meditation music all to hand. I find the drip makes me quite cold and there is an air conditioning duct right over the bed which becomes chilly if I am just lying there. I also stagger in with my pillow as well because the nasty plastic covered ones are uncomfortable. They are all used to me now and I just joke about it all.

However, it is welcoming to feel among people who care. And I will miss my visits. In some ways, it is almost the only outing I have. I find myself becoming more and more reclusive as I have to devote such energy to my cancer. The only other places I go are to the supermarket when prompted by almost running out of essential items, to the pharmacy or health shop, in both of which I find friendly and sympathetic friends, and to Dr. Chen once a fortnight for my Qi Gong massage. Once I am out, I quite enjoy it, but I find myself putting it off. Partly it is because I am just so busy with my struggle and with all the work we are trying to do to get our books published. I don't even seem to find the time to contact people I should or keep up to date with things. Naughty! I like to keep in touch. But there is nobody.

I will get over this minor depression. It is hard. However, I will cope. I am worried about the stage of

my cancer, though. This seems to be a time of year when cancer grows faster. Must be the spring!

One thing I would like is another MRI to see if things have deteriorated. I need to have it done before Ric goes so that I can discuss the results with him.

1st October 2004

Ric got a referral from the specialist who originally saw me and I managed to get an appointment with just enough time for the results to come back on his last day.

It was really quite friendly at Auckland Radiology MRI. The technician came out to the front desk and said "I know you. I have done a scan on one of you just recently." Of course, Brian had had an MRI on his eye just a couple of weeks before. Still, it was a friendly approach and a far cry from Auckland Hospital MRI where they had tried to prevent Brian from even coming down with me to the area. There he was told to just wait in the café. I was distraught and said I wasn't going to have it done at all. Actually, I was stunned because he had been allowed in the previous time. Now with their new fancy hospital, patients seem to come last.

I commented at the end how pleasant it was at Auckland Radiology compared with the hospital. Their response was "Oh yes - a man of few words...." referring to the technician at Auckland Hospital. Certainly his bedside manner could be improved. Does he not realise how stressed people are when they come for these procedures?

It makes you think when you go to these places. There was a very sick girl brought down from the hospital in her bed, worrying about whether she would have to wear one of their gowns. Her parents were with her and there was going to be a long wait. Another little girl was there with her whole family who just ignored her. She had just had a central line, I think, inserted and seemed very drawn. Some people there look really ill - one man really gaunt and only just hanging onto life. I felt almost a fraud as I look disgustingly healthy. As my daughter says, I look in better health than I have ever been. It is just that I have this thing inside me which could easily kill me.

This MRI was more difficult than others in that they kept asking me to hold my breath and hardly gave me time in between scans before the next breath hold. Apparently my tummy was gurgling and they were having trouble getting clear pictures. I thought it would never end. I was surprised part way through to have a woman's voice speaking to me instead of the original man. It turned out they had changed shift in the middle - a bit disconcerting

I didn't realise until afterwards that poor Brian was in difficulty. He had come into the scan room with me to make notes and for company. Just as he sat down, the lens had come out of his glasses and, although he managed to locate the screw, he could not tighten it sufficiently to keep the lens in place. The thread had been stripped by an incompetent optician when he had gone to have it tightened a few months back. He is virtually blind without his glasses and so had a big problem. The strange thing was, though, that it was the lens of his bad eye, the one

with the tumour behind, that had fallen out and made him almost blind. He just could not manage with the one eye only.

We asked if anyone had a small jeweller's screwdriver to fix the lens. No luck - but they suggested the Wallace Building just across the car park. It was the Eye ward and they might have one. Again, nothing doing. But it was strange to have to go into the Eye Surgery ward. It also gave the strong message that anything to do with radiology would be a disaster and that, like me, he was better off with no intervention. We discussed this as I drove home with my half blind passenger. At home we had everything we needed and were able to effect a reasonable repair.

While he was struggling to see in the hospital, I had asked the radiologist if I could possibly see her for a bit so she could explain my films to me. I told her about my subjective feelings of where the pain was worst and she said that would help her when my latest films came through as they took a bit to process and come onto the computer. Meanwhile, she said to come in and she showed me the previous scans which had been downloaded from the disk I had got from Auckland Hospital.

It was really helpful as she pointed out the extent of the tumour and pointed out how it was blocking the exit from the uterus and causing a build-up of rubbish inside. I do find it invaluable to be able to visualise the tumour so I can work on it. Brian tried to take a one-eyed photo of it but he was really operating under an enormous handicap so it wasn't up to his usual standard.

The question was - what were they going to find this time? Had it got worse in the seven months since my last scan? Or was it improving. I was scared because things did seem worse and this would be a moment of reckoning. I couldn't hide from the results or pretend to myself that things were OK. They weren't even sure until they saw the films processed whether I would have to come in the next day for some extra scans to get a clearer picture. Anyway, I should have the results by the time Ric went away so I had made an appointment with him for that afternoon and asked MRI to fax me the results as well.

As it turned out, they faxed me the results the next afternoon. I was pretty depressed by them as the tumour was still growing upwards although it did not appear to have spread outwards at all. That, at least, was gratifying. I suppose I had hoped it had got smaller, although I hadn't really held out much hope of that, given the bleeding and pain. So I suppose this result was the best I could hope for.

When I went to see Ric the next day, his first comment was : "Well, you should be pretty pleased with that. The rate of growth has slowed down a lot." Actually, when Brian did actual volume measurements as a cylinder or a cube, it showed that the growth rate was now 4.1 cu cms per month instead of 6 cu cms. So it was not as good as Ric had thought at first glance. However, by this stage of cancer, I would have thought the growth rate would have been exponential rather than slowing down. So, all in all, it was positive, I suppose.

On the Mend?



2nd October 2004

Scary! I am on my own with no medical support. My bleeding seems worse. I am still in pain. It seems like drastic measures have to be taken.

It is really good that I had the MRI explained to me. That way I can strongly visualise the problem and my body solving it. I can sense the top of the tumour folding over and getting smaller. I can feel that I must open up and let out all the cancer products.

I sit at my computer and put my feet in an old fashioned hot mustard bath. I can feel it pulling and also an easing in my back. It must be doing something. I repeat it.

Back to the very hot baths, too. But now I have refined it. I spent ages in Payless Plastics trying to work out if I could fit into a baby's bath so that I could make a hip bath. You have to laugh in this game. There are so many funny situations. Luckily I discovered what looked like a washing basket but all filled in like a tub. It was the only one. When I tried it, it just fitted into the bath - perfect! And talk about colour coordination - it matches perfectly the pale blue bedpan I had originally got from an opportunity

shop ages ago to use as a footbath so I could carry it without spilling. This now is used for its original use with the coffee enemas and, after scalding, with my mustard footbaths.

4th October 2004

Anyway, back to the hip bath. I part filled it and chucked in a decent amount of yellow mustard powder, then gingerly parked my posterior into it. Whew! Hot! But it needed to get hotter - up to 45 degrees. I put in a jug of hot water from the tap at a time - 15 in all, to bring it up to heat. Then I leant back and read my book, stopping when the water cooled to top it up again. With the plug in the bath, the spillage stayed in the bottom of the bath and so I got a footbath as well, only a bit more dilute.

But it worked! I was quite perturbed to find lots of big, dark clots as I leant forward to fill up the jug. Were they bits of cancer, dead inflammatory tissue or just blood clots? I hoped it was bits of cancer. It just kept on coming until I had collected a whole specimen container of this tissue. I was a little afraid, and yet I felt it was a good thing. But there was nobody to ask. I had to just trust my instincts - but I guess that is what I have had to do all along.

The interesting thing is that the bleeding seemed to have stopped and there was very little leakage of fluid. So, the next night, I repeated the exercise. Again, more clots, but far less this time. The next time I tried it - nothing! I reckoned I had fixed it - at least for the time being.

And all this had come about from having

someone take a few minutes to explain things to me so I could influence my own body. That radiologist was quite sympathetic to what I was doing, even as far as saying that there was no guarantee I would be any better, even if I had had conventional treatment. That made me feel better as I find the constant pressure from those who know best, the senior doctors, is such a strain and tends to knock me off balance.

I felt so much better after this weekend of cleansing. My body must have been struggling with all the poisons from the waste products which couldn't quite get out of my body. I have often thought that it is so much better that I can pass rubbish out of my body rather than my liver having to struggle with it as it would in a different sort of cancer. This showed me the truth of that supposition. I felt lighter - in body and in mood. I could bend over without feeling a sort of lump in the way. I felt more confidence. Everything was brighter. And my energy came back.

Perhaps I was on the mend! This was a real boost. It was a shame Ric was away as I needed an examination to see if the size of my uterus had gone down.

Eventually, I was so excited, I could wait no longer so I made an appointment with one of the other doctors who confirmed what I had felt. It was almost back to its normal size - a bulky uterus. This was incredible. Now I just need to keep it up.

The Blackbird



29th November 2004

Yesterday I was woken by the shrill warning chatter of blackbirds, the way they do when there is a cat around. However, this time it was desperate and just outside the bedroom window. I dashed outside to find, as I expected, Leo being dive-bombed by two angry parent birds who were chastising him roundly. I chased him away and then realised he had turned his attention to the guinea pig cage on our lawn. Huddled up against it was a baby blackbird which I picked up and held protected against my chest. The parent birds kept swooping low and Lucy, our mother cat and her kitten were a little bewildered as they had just come out and found themselves under fire as well. Leo immediately went back to the previous place by the fence, expressing so much interest that I thought there must be another one there. Sure enough, there it was, pressed hard in behind a branch, with its wing jammed.

What was I to do with two baby blackbirds? I knew the parents would not look after them if they had been handled much so I put them out under some bushes where the cats couldn't get to them

but the parents could. All the while I was looking over my shoulder to make sure I wasn't being observed by Leo. That seemed to be that. I stayed on the deck, doing my Qi Gong exercises and watching to see if the parents found their young - and they appeared to do so, hopping onto the fence and then dropping to the ground with a worm.

I went inside to have breakfast and was suddenly aware of the furious uproar out the front again. Leo was at it again. There was a baby blackbird on the lawn. Was it one of the ones I had already rescued, or was it a third one? I decided to hold on to this one and searched for the other one to no avail. What a stupid place to teach your fledglings to fly - in a garden with four cats all watching and waiting! And the birds knew this too as there was often a commotion when a cat strolled into view. Leo would torment them by just sitting in the middle of the lawn in full view.

I couldn't get over how active this little bird was. It hopped and called, sat on my finger, tried clumsily to fly. It took a little cat food which was better than being cat food itself. I put it in a box with some hay that happened to be still on the back deck from when I had nursed my sick mother guinea pig. When I went down to my office, I took it with me and it sat on the edge of the box for a bit before flying down onto the carpet and wandering around, trying to get out through the French doors. It was a real delight, though it kept calling and wouldn't take any food.

Eventually, I took it out the front where Brian was working on the car. The parent birds were still there and I hoped they would hear the baby call and

come and look after it.. I put it on a thin branch of a tree where the cats couldn't reach it and just watched. It called and the parents flew round it - but they didn't feed it. I noticed they were flying to a different tree and then dropping down to the ground after watching carefully all around. Then I saw they would come with a worm. They must be feeding the other one. I crept up and saw it sheltering under a plant.

Well, if they could give whole worms, then so could I. So I went digging in the compost heap and came back with a dozen worms. I tried washing them before offering them to the baby but they just slipped out of my hands - the first one on the lawn on the way across and the second while trying to give it to the baby. Oh well, I suppose the parents can't wash them. So I just wiped them and immediately the baby accepted my offerings. In the end, it took five worms. It was starving. The parents watched but didn't bother to help. It appeared I had to be the mother.

At nightfall I brought it inside and put it in its box. It had been asleep on its branch but I knew that it would go to the ground in the morning and call and that would be that. I didn't know what to do about the other but decided to let it take its chances with its parents and the cats. I did worry about it though and felt especially bad the next morning when it was stiff and soaked beside the path.

My little black bird was determined it wasn't going to stay in its box. It sat on the edge of the box for a bit while we had our evening meal then took a short flight over to the edge of the washing basket.

It judged it beautifully. The only trouble was that it was slippery plastic and its claws didn't grip so it slid into the basket. It hopped around in there a bit among the oranges and grapefruit I had just collected from the garden. It was covered by the other washing basket plonked on top. Eventually it became still and I found it had gone to sleep.

This morning I was awakened by the indignant cheeping of a bird wondering where its breakfast had got to. Luckily I still had some worms sitting in a bowl of earth so was able to oblige almost immediately. We managed to get some photos of it feeding. Then it sat on the edge of its box and snoozed. At any movement in the room, it would wake momentarily and cheep, then snooze again. It must have been exhausted by all its excitement yesterday.

It is incredible to watch it, especially when it fell asleep. Three claws grip the front of the branch with one at the back. This back one flexes up and down to keep the balance, even when it was asleep. It is a totally reflex action and I watched the same on my finger when I could feel the flexing and pressure from the toes as I moved my finger. What a brilliant piece of design. I had often wondered why birds didn't fall out of trees when they went to sleep.

I went to hang the washing out and Brian was doing photographs of our papyrus paintings to illustrate the book we are in the process of producing *Ankhsoun, Daughter of Ra*. We could then scale them on the computer and use bits in the book. I used to have a papyrus paintings business called Nile at Hampton Court near London so I have a wonderful collection of paintings that are not available now.

That business was how I met Brian when he answered an advertisement - he jokes that I advertised for a husband! Cheeky!

When I came back up to the house, he called out sadly "I think I've hurt the bird." He had been photographing some of our statues and had reached over to put one back on the shelf and moved his foot slightly. He heard a cheep and realised the bird had flown down beside the chair, unnoticed, and he had knocked it. It now sat hunched, although still strong. Sadly, it deteriorated very rapidly and became colder and colder. Perhaps it was shock, although it had had a worse time with the cat yesterday. Perhaps it was for the best though. I just do not have enough time and how was I to have kept it safe from the cats while it learnt to fly? And then it was so tame and had absolutely no sense of danger. So sad though, and Brian was devastated. He loves young things. It is just a shame they grow up and do things like Leo, hunting for fun.

It was only a few minutes before I had to go over for my Vitamin C drip that I found the bird had finally died. I was sad and felt a bit low. However, the drive is over the hills, through the countryside and my spirits started to lift. It was strange. I felt as if I were travelling a few feet off the ground, totally at one with the world. I contemplated the frailty of life. One minute there was a warm and responsive little creature, fully trusting. And then there was a cold and lifeless little thing, lying on the hay in the bottom of the box. Every feather was perfect. You could see its tiny ears. It looked so odd as its tail hadn't grown. Each tiny bone in its legs was visible, as well as the joints and ligaments,

all covered with the faintest downy fluff. Life is so short for some. But it had given inordinate pleasure for the 28 hours we had looked after it, and hopefully its end was better than its sibling. At least it was held and stroked and spoken to rather than being terrorised and eaten.

But for some reason, I had this incredible feeling of oneness and union. It was as though my place in the world was secured. I knew I was part of this wonderful whole composed of all the plants and creatures of the natural world. I always feel at peace when I don't have to interact with people. Animals and birds, and even fish are more responsive. It is an incredible feeling, though, to feel so much my place in the whole, to feel that I was being cushioned somehow, and I was fulfilling whatever purpose I have here, even if it is just going about my normal life and fighting this cancer.

Having cancer and making the decision to overcome it in this way have given me an enormous strength and have made me so sensitive to life and death, to all the little nuances. I watch and observe. I feel joy at the evening light on the paddocks, the sudden soaring of a falcon above. Each day when I go down the garden, there are myriad birds all calling their joy of life. I watch the changing seasons with pleasure and anticipation. And I have a part in this rich tapestry. I am still here, against all the odds. And I am smiling and content.

My drip went through so quickly in spite of an inauspicious start when it wouldn't flow properly. I managed to get in over an hour's sleep which was good as I had worked until almost 2 am on setting

Ankhsoun's book and putting illustrations into it. I was shattered. I missed chatting to my friend in the dairy which had always been part of coming over for my weekly drip. I would buy a forbidden icecream as my one treat and chat to the owner. But they have sold the dairy now so I no longer have that to look forward to.

And on the way home, there was this wonderful, peaceful feeling again. I stopped for vegetables and felt such pleasure at the array on sale. I really enjoy going to that shop and make a point of getting everything fresh on my way home. They have unusual fruits and vegetables that I occasionally try too. The summer fruits are just coming into season - cherries, blueberries, strawberries, raspberries. It reminds me of my allotment garden in England where I had rows of berry bushes - gooseberries, black and red currants, blackberries, blueberries, and more strawberries than we could possibly use. I was just giving them away. I can't grow these wonderful fruits here as the climate is too subtropical.

Not that you would think so at the moment. From swimming at 30 degrees in the solar heated pool at the end of October, we have gone back to under 20 degrees. And the wind is icy. The old saying "Ne'r cast a clout till May is out" is so true, except that Downunder it is November.

We have lost the magnificent cumulus clouds of late winter and gone into the heavy grey clouds of early summer, complete with wind, rain, hail, etc. Everything is thrashed by the weather.

Still, I am content. I am still healthy and have this feeling of riding over everything, cushioned

above the ground, a bit like a hovercraft, I suppose. It is hard to describe. But it feels good. And I know things are right, even if I don't manage to overcome my cancer. Whatever happens, I am sure that I am fulfilling my destiny. And I can take charge of my own life and use what I have left of it in the way I feel is right. And when my work here is done, then I can go in peace.

Remaining Steadfast



2nd December 2004

During the compiling of this book from things I had written at the time, when the emotions tended to overwhelm me, it has rather surprised me how wild were my mood swings. I went back and forth from panic to calm; anger to acceptance; anguish to peace; fear to joy; deep depression to a quiet pleasure in life. These extremes of emotion are very plain in the sometimes desperate and sometimes joyous things I have written.

I suppose these are just exaggerated versions of normal life. However, when faced with a life-threatening disease, things tend to have a greater immediacy. It is the little things that make an impact - a niggling pain causes more fear than would a simple stomach ache in earlier times. Is it the cancer getting worse? But conversely, the sound of a bird call, a beautiful sky or a delicate insect will all cause such a feeling of wonder at the beauty and enormity of life. Every moment counts and every feeling is experienced keenly.

During the journey, I have remained steadfast, holding to the faith that I can get well again, that

everything serves a purpose. Whatever the outcome, I have gained so much in strength and understanding. I have learnt to overcome fear, to relax against pain and worry, to look inward to myself and upward to God. These are the only places in which I can truly place my trust and find the help I need - although I do take note of medical advice and evaluate it. My experiences, though, mean that only too often trust in this source is lacking.

During the low periods of my journey, the periods of doubt, I have often found myself uplifted by reading other people's accounts of their own journeys with cancer. I would then think AWell, if they can do it, then it is not as impossible as it is made out to be by conventional medicine. So maybe I can do it also.@ I would take elements of how others have coped and adapt them to my own life and my own philosophy. But the knowledge that others have succeeded is important to me.

My aim in writing this book is perhaps to add to this wealth of help, to show how the wild swings of feelings are a natural part of the struggle. And also, there is the necessity for self-help, to harness all the resources of the mind, body and spirit in a glorious burst of energy and to keep the impetus going until everything is hopefully healed.

In the course of this book, I have confided much personal information but I feel that by hiding it away in shame or fear, I would not be able to do justice to my attempts at healing and the reader would not be able to understand what lay beneath my decisions. I have to trust that my story will be treated gently and with respect.

I have tried many different methods to overcome this cancer. I feel it is important to work out for one's self a combination of ways that feel right and that can fit in reasonably with one's own personal circumstances. There is no use in trying to do something that ultimately causes more stress. The overall feeling should be of doing something positive, albeit something which may be difficult and needs discipline. But hopefully there will be a feeling of confidence and faith and a trust that all will be well.

I give later a brief summary of the things I have found to be of most help to me. I know I should perhaps be more disciplined. And I do try to be - in bursts, but discipline has never been my forte. Also it takes me all my time to do what I feel I must do in my life, trying to fulfil its real purpose. The cancer has certainly served to highlight the urgency of this and caused me to focus more on it.

But I am truly grateful to have had this opportunity to review my life and my living. I feel it is a privilege I have been granted, although sometimes it seems very much a two-edged sword.

The strange thing is that I have found both strength and peace.

Hold to the Hand of God



The following poem was sent to King George VI just when he was pondering what to say to his people throughout the Empire. It was late in 1939 and he was preparing for his first Christmas Broadcast of the Second World War. It is a clear example of him being given what he needed just when the time was right.

The words he read have a power which speaks to me and which echo my own sentiments. It seems to me a very appropriate way to end this part of my story.

*And I said to the man
that stood at the gate of
the year:*

*"Give me a lamp,
That I may go out into
the dark unknown."*

*And He said unto me:
"Put your hand in the
hand of God,
And that will be better
to you than a light,
And more sure than a
known way."*

Minnie Louise Hoskins (1875-1957)

Part III

Helping Myself

.... and Others

Self-Help



For those readers who are interested in ways they can help themselves to fight their cancer, or merely to feel better and more positive, I now discuss many of the things I have tried and my own adaptations. Everyone is an individual so what works for one, may not work for another. However, it is worthwhile experimenting a bit to find what best suits what you can reasonably fit into your life and your financial situation. For fighting cancer is not cheap. However, there are many things which cost little financially, but a lot in time and effort.

Over the past four years, I have read so much on cancer and on general physiology to try and understand the processes going on in my body. Fortunately, it is a subject which has always interested me, unlike poor Brian who is bored rigid by things to do with the body. For him, it either works or it doesn't. Give him something mechanical or numerical any day. I have the same feeling about those. If it isn't alive or part of the natural world, I just can't get my head around it. However, I will spend hours with a sick animal or nurturing plants - or even just wondering about the clouds.

Although we had always had a pretty good diet, mainly cooked fresh, with a good variety, I immediately tried to improve its quality. Brian is very much a meat and two veg bloke, whereas I could live on soup and salad, as I mainly did in

Africa where the vegetables come round fresh each day in a huge tin basin on a woman's head - so heavy it takes two women to lift it back up. However, I had tended to cook what Brian required. He is thin and wiry – or was until the Prednisone got to him - and uses so much brain energy that he is always hungry and would be happy with two cooked meals a day. I prefer to graze. So I guess, over the years, my diet has changed to what is less than optimum for me.

As soon as I found out about the smear, I started on an anti-oxidant supplement regime but I wasn't sure about what exactly what I needed. It was all on feel and what I could glean from books. I was given guidance about using Indole-3 carbinole as this can change the oestrogen pathways and research had shown that it could reverse the earlier stages of cervical dysplasia. So there I was, stuffing myself with cruciferous vegetables and carrots, hoping that it would reverse whatever damage there was.

But then came the actual cancer diagnosis. This obviously needed stronger measures. They say to relax as stress makes things worse. Relax! When you have just had this devastating news and are casting round to try and find what you can do! Oh, well. I could only try. Then I was introduced to Brett, a homotoxicologist newly arrived from South Africa. He immediately put me on the strictest diet with instructions to not bother coming back if I didn't follow it to the letter. "Go away and have a last meal," he said. Then start it tonight. Rice and cooked vegetables for three meals a day!

I soon learnt to put a tomato on top of my rice towards the end of cooking so that it broke open and improved the flavour. And I got pretty good at making soups - but then that was nothing new to me. But now I wasn't even to cook with salt - only sprinkle a little herb salt on the meal itself. After a week of this which didn't give me much reaction, probably because I

had already made an attempt at detoxing, I was allowed to have some variety. Yes, I could have a rice cracker with avocado and acid free tomato for morning and afternoon tea. How I relished that.

And Brett put me on a regime of supplements too.....It is wise to seek individual advice on this, though the general ones will include the anti-oxidants. I have also found the B group of vitamins helpful, and am generous with my fish oil supplements.

The diet was increased in variety but still relatively restricted. There was no bread, butter, salt, sugar....all the things that made life worth living! And these were the things that Brian was always nibbling at to satisfy his constant need for food so it was tempting and they were always around. However, I was very strong and managed three whole months like that.

I would probably have been able to keep it up much better if I hadn't taken a second job which was very stressful and didn't fit in with my own body rhythm. I had to be up too early for me which meant I didn't sleep well. There was too much to do and I got erratic breaks. This meant it was extremely difficult to keep to a strict diet.

I do find that it is essential for my good health to go with my own diurnal rhythm. For me, this means getting up late but working far into the night when I feel at my best. I don't know why, but my best sleep seems to be after dawn. This does, however, make it difficult to have a standard job. It is essential to reduce stress, not increase it as I did. But I was riding high at the time and feeling very confident.

During this time, I met my new GP who is very supportive and spends time thinking about what could help me. He makes suggestions from papers he has read, and I test these with my pendulum. This is a good way to check if supplements or foods are good or bad for you at that particular time. I would

recommend learning this technique. Of course, you could also use muscle testing, but this needs another person. Anyway, I started on weekly Vitamin B12 injections which do give me energy. But Vitamin B12 also work synergistically with Vitamin C so for me it is important.

The weekly visits where I could discuss my fears and check that I was on course were invaluable. I was able to build up a relationship with someone who was prepared to walk the walk with me, even if that meant walking with me right up to my death. I did not feel alone. I lost touch with Brett and used my GP for supplement guidance and as a sounding board for anything else I thought might help. It is essential to find someone you can trust, someone with whom you can be totally honest about what you are doing so that they know your full medical history and what supplements you are taking. This is vital if you need medicine or perhaps surgery as some supplements could have a detrimental effect in these circumstances.

So there I was, adding some supplements to my list. From time to time I use my pendulum and run a check on them. I will stop some for a while, start others again. I feel my body needs different things at different times. I came across a wonderful analogy in a book which, to my shame, I cannot now remember which one. This said the bloodstream was like a smorgasbord constantly passing every cell and each cell could just choose what it needed from the array of nutrients passing by. I found visualising this helpful. I also found it useful to know what each supplement does and then to visualise it going to the cancer and helping there.

The same thing with foods. It is good to prepare the meal lovingly, eat slowly and thoughtfully, chewing each mouthful well and thinking about the food going to where it is needed. Sometimes when I eat something, say an orange, I think "There is all that Vitamin C going to help my body." But I know it is

more than just Vitamin C. There is all the fibre from the segments and this contains a wealth of bioflavonoids. Then there is the oil in the skin as I chew a bit of that. And then there is the anticipation as I peel it and the pleasure of the distinctive taste of the juice. So eating can be an experience which helps on many levels.

Actually, visualisation is one of my strongest tools. I first learnt it when I met Dr. Chen and started having Qi Gong therapy. In this Chinese treatment, it is the intent as you do an exercise which gives it strength. I can use this technique to reduce pain, to relax, to shift bad qi or toxins from my system. I feel so invigorated if I actually spend an hour doing the exercises. And I enjoy using my mind to help the healing process.

I adapt the Qi Gong breathing techniques. I breathe in 'through my whole body' and then direct the breath out through my cervix – or anywhere else I may have pain. Or I reverse it and breathe fresh energy in through my cervix and then disperse it out through my whole body. So I am concentrating on my breathing and directing the breath to where I need it. This is very restful and focuses the mind beautifully.

In conjunction with this, I also try to spend a while meditating every day. I am supposed to spend an hour and I really find benefit if I can manage this. Time constraints prevent it often. Or sometimes I am so tired, I fall asleep which is not what you are supposed to do. I am gradually getting better at this technique, though and can certainly find it helping.

For the visualisation, I hold my hands over my lower abdomen and feel the cancer getting smaller and smaller. I work all over it from the edges into the middle, from the top to the bottom and can feel each bit as I work on it. Basically, I am focusing my energy on one small bit of me, where I feel it needs attention. And I can mentally stroke it, or mentally squeeze it, or whatever. But I do feel a gentleness towards my cancer and

find I don't want to visualise anything violent towards it. I find it really good to listen to my tape of piano music while doing this and I can feel each note striking a different bit of the cancer or the good tissue round it. It is worth experimenting with different types of music to see which suits. I find some orchestral music helpful.

One of the things I have found most helpful has been the coffee enemas. Ugh! you might say. That is what I thought until I tried it. It is quite amazing how light I feel after spending half an hour. My colour is really good and my skin and eyes look clear. Headaches or other pain seem to melt away. For myself, I find the best times are after lunch and after dinner, although some schools of thought say after breakfast and lunch. But then I am not a morning person and tend to work late at night so I am not affected by the caffeine.

It has now become my relaxation time as I get myself into a hot bath, with a handful of Epsom salts (bought by the sackful) and perhaps some essential oils such as Lavender or Geranium. Then I introduce the nozzle and relax with a book. I have got through quite a bit of reading matter in this way. Sometimes it is a book on cancer or nutrition, but sometimes just a magazine or something light. But I totally relax, often listening to orchestral music if Concert FM is playing something I like.

The old wife's tale of mustard baths and mustard footbaths is worth looking at. I find I can really feel the pull through my feet of the mustard. Finding the tub for a hip bath was good as I could make the water much hotter and then I tip it out into the bath and have a full body bath, but cooler.

I have tried having really hot baths to try and push my body temperature up to the point where the cancer is killed or injured. It is OK but I am scared to do this unsupervised as my heart pounds and I pour sweat. It can get so I am almost passing out. With supervision, this would be good.

For my particular cancer, I use a selection of condiments. My bathroom looks a bit like a kitchen. Manuka honey and turmeric makes a good application. I found that cayenne did stop the bleeding – but it is hot! That skin is pretty tender! I also use colloidal silver, either in liquid or a gel. And then there is the tin of mustard and the Epsom salts, the almond oil and the castor oil..... It takes over from the toothpaste and soap.

I use essential oils applied direct or in the bath, making up various mixtures for different needs. The Bach flower remedies are also useful for my mood. My daughter gave me a full set and I use my pendulum to determine which ones I need – or my family. Incidentally, these are also great with animals.

Stress is to be avoided at all cost. I am now much more laid back and if we have a row, I try not to let it go below my waist. In general, I can walk away from things more. It is worrying sometimes as I feel I am just riding over the top of things. But the calmness shows and I find I have a smile on my face more often than not. I consciously relax and mentally smooth out the frown lines. I have to keep reminding myself as my face can be quite tense – as can my shoulders and neck. So it is good to be aware of this tension and keep a check on relaxation.

I do get very tired and have learnt to pace my day. I find I work best at night when I am more clear headed. This means I don't get up until 8-9 am but that doesn't matter. I think that when I had a job and had to get up, that was what was more stressful than the job itself. It didn't fit in with my body rhythms.

Perhaps the most important way I am helped is through my strong belief in God. I am having to truly live my faith and do my best to keep myself as well as I can. But I am aware that my life has a purpose and that I have a destiny to fulfil. I find this understanding takes away the fear and anxiety I would otherwise feel. I feel a calmness and a peace. And time and again

I am shown by little signs and coincidences that I am on the right course or that I have done the right thing. It is very reassuring and I look to these for guidance whenever I have to make a decision.

Brian gives me hands-on healing as well. I can feel the energy in his hands and the calmness which it gives. I also do this for him, too. It has not been as frequent of late as we have both been working ridiculous hours and bedtime means sleep time.

Generally, I have changed my life to take more account of what is important, what I need to accomplish. I try to make my time count. Cancer is a great teacher. It forces one to live more in accordance with natural rhythms and to think about what really counts. I do not resent having cancer. I am angry sometimes at the way I have been treated and that it was not detected earlier, in spite of all my efforts. However, although anger helped energise me in the early stages, it serves little purpose now. But I have learnt so much.

I hope these general notes are of some help for guidance. Each one of us is different and needs different things. It is of value to read as widely as possible and I append a list of the books I have found helped me at different stages, with some brief comments about them. It is essential to find a doctor or other practitioner whom you can trust to guide you. However, it is you who will have to do all the work, really.

It is your body – but also your mind and your spirit. Cancer gives a chance to integrate these and to feel whole, in spite of the body not being as you would like. And if you are able to feel your place in the world and the scheme of things, you will feel the "peace which passeth all understanding".

Then, as will happen to all of us one day, the body will not be of any consequence. We bring nothing into this world and it is certain we can take nothing out of it, save our souls. But the

way of our living will determine the way of our dying. With this peace and understanding, the parting is more likely to be gentle, with a feeling of readiness for what is beyond. The spirit can soar away, freed from pain, but richer for the experience.

Cancer has helped my spirit to develop. Ultimately, my body will not matter one jot. It is merely the temporal abode for my soul in this earthly life. Our research has shown us, without doubt, that the soul can survive death. So it would appear that my cancer is part of the process which God has seen fit to use to strengthen my soul.

Postscript



There must be some purpose to this cancer. Nothing happens by chance. So it is up to me to work to help in this field.

I have participated in the Cervical Cancer Audit which is seeking information about the effectiveness of the Cervical Screening Programme in New Zealand after the problems in Gisborne. Every woman who was diagnosed with cervical cancer over a two year period was invited to assist. And at last all our smear slides have been sent to Australia for controlled rereading. It will be illuminating to see the final report when it comes out late in 2004, as I understand.

I did feel that it would be a good thing if each of these women, or their next of kin if they have died, are sent a form, seeking information on the stage they were at when diagnosed, the treatment they had, how they found that - side effects and effect on their quality of life, and whether they are well now. This would provide valuable information about treatments as well. However, as it is not in the brief, I don't think that this will be done. What a wasted opportunity!

I feel that it is a great pity that women are not advised of diet and lifestyle changes at the first sign of any cervical abnormalities. I have found that they are just glossed over and the woman has no idea of the potential seriousness of the situation. If these changes are made early enough, then a

progression to worse stages could be avoided. I would love to see some sort of advisory centre about this.

It would be very good, also, to have some sort of support group. It is a cancer that is often hidden with shame since it now has the connotation of an STD. That is not necessarily the cause and that has caused pain and shame to many a woman who then feels unclean. Women need to be able to talk among themselves and exchange experiences and ideas for keeping themselves healthy.

I am deeply upset by the proposed legislation to remove the right to privacy of records for those diagnosed with cervical cancer., this has now become law and is such an invasion of the right of privacy. I wrote to Annette King but the reply was a whitewash. It has been decided by a select committee, against the advice of doctors and others in the field. I reproduce below my letter. I urge anyone else who is affected or who feels that this is an infringement of civil liberties to also make their opinions known to Annette King.

14th November 2003

Annette King

Minister of Health

The Beehive

WELLINGTON

Dear Madam

Cervical Screening Research

Parliamentary Bill on Access to Medical Records

I am most concerned at the imminent passing of a Bill giving researchers access to the medical records of those with cervical cancer. When it was first in the media, I immediately took steps to have my name

removed from the Cervical Screening Register. I tried to make enquiries about the bill but got nowhere.

After this latest publicity, I have contacted my MP, only to be told that it is too late for submissions. However, I hope that you will take what I am writing into account as I am one of those very much affected and I feel it is a gross infringement of my rights and of the rights of others in a similar situation.

You see, I have cervical cancer. Not only that, but I had 5 clear smears before it was diagnosed. This was around the time of the Gisborne Inquiry. I had had previous laser treatment in England and only realised there was a problem when my husband got hold of my English medical records that the clinic was trying to contact me to ensure that I had regular follow-up because a later smear still showed a bad abnormality. So, when I had these smears here in NZ, I had assumed that something would show up. I mentioned this to both my GP and my gynaecologist and gave them each a copy of the English specialist report but was told that ANZ has the best laboratories in the world. The smear readings must be correct@. I was not satisfied with this response and continued to be worried, especially when the Gisborne question arose. I again queried my results and got much the same response.

Finally, one of the best laboratories in the world lost my sample and so they had to redo it - and this at a time when I was experiencing what I now know to be worrying symptoms. Consequently, 6 weeks later, my GP did another smear and, as it was at the laboratory expense, he did a Thin Prep smear. This

showed gross abnormalities and I was rushed off for colposcopy, biopsy, cone biopsy, etc.

I was naturally very angry at not having been listened to. However, I determined to put my experience to some good. I tried to publicise it because, at the time, the government position was that it was only Gisborne and the poor bloke there, Bottrill, was being sacrificed. I had also had such a bad experience of the health system by now that I did not have the confidence to put myself into its hands and have radical treatment. As such, it was of extreme importance to me to find out as much as I could about my previous smears so that I could determine how fast my cancer was growing, and therefore how I should go about my treatment. Perhaps not unsurprisingly, I could find out very little. I had an offer from an Australian lab to reread my slides but Diagnostic would not release them here. I was told I would have to wait as the government was going to do an appraisal of all the slides. That was of little use to me, as I needed this information to make an informed clinical decision for myself - then, at that time, not some time in the future. I had to go without that information and just trust my instincts.

I contacted the researchers in Dunedin. I contacted the NZ Herald. I contacted Sandra Coney. I contacted the lawyer acting for Colleen Poutsma in Northland. I contacted someone in the Department of Health. I got no help at all. And, in fact, in the last case, I didn't even get the courtesy of a reply. So, I was on my own.

My husband and I went to see the head of Diagnostic to try and find out about my smear

readings. I was refused the information I needed, ie. the results of their internal audit of my slides for medico-legal reasons, in other words, a cover-up for their incompetence. However, ACC makes the whole health system loaded against legal action by those who have been damaged by incompetence within it or by contracted service providers. Anyway, I have no energy to fight the system. I need every ounce of that for my own survival. The fact, though, that I was unable to access information I needed to help me make an informed choice over my treatment for my cancer is an indictment of the system. The patient is just there, it seems, to provide a living for the service providers and the patient's needs come at the bottom of the heap.

Now I really object to some third rate researchers having access to information about me which I was unable to access myself. I find that insulting in the extreme. Surely my immediate needs - i.e. how I should fight a deadly disease - should have meant I could have access? Surely that is of more importance than statistical research? In fact, I was told that my slides and biopsies, although a part of my body and which I paid to have taken, do not in fact belong to me!! It seems they belong either to the laboratory concerned or to the government! I find that incredible.

I have seen for myself the standard of that research. I tried to give anyone who could make use of it information that would perhaps prevent the same thing happening to others. They didn't want to know. The researchers in Dunedin wanted me to make all the running and write it all up for them - at

a time when I had just been diagnosed and was fighting hard for my life! If they had come back to me and asked questions, I would have been happy to answer them and do what I could. But they didn't bother.

I am now involved in the Cervical Cancer Audit. That is just so frustrating. I was one of the first people they interviewed and found it so ridiculous. I gave the interviewer a typed list of all my smears, with the laboratory and reference number for each, as well as the reported findings of each. In spite of this, she had to go through, asking the same questions about each, where did you have it, when, etc. She even asked me what my address was when she had come to my home to interview me and knew it was my home!! My husband just walked out in disgust at this carry-on and has had no respect for the audit since. He is a research scientist himself and couldn't believe how amateurish and incompetent it all was. Why could they not relate the questions to the situation so that they got all the information needed in the most efficient way? Third rate would be a generous description of the ability of the woman who came to do the personal interview. She was unable to grasp the points I was trying to make. If equally capable people are involved in other stages of the survey, I for one question its value.

The final straw for me, which caused me to completely break down and sob, was when I was told the results would probably be presented at a hui on the Marae. How PC! No! I would like to attend a proper, professional presentation of the results of the survey, not that I feel they will really be of any

real value, and I would like my own results personally explained to me. I am not Maori and would rather have something more in keeping with MY culture which seems now to be second class. I understand and respect other cultures, but my own needs and culture should also be respected.

Apparently my slides (all except for one) have now gone to Australia and been reread. I still can't find out the results because they have to be reviewed here, along with the control slides, for statistical purposes. That is not much use to me. However, they could not find one of them at Diagnostic. I was phoned about this and realised that it wasn't done there anyway. It was at Delphic and this was clearly marked on the sheet I had given to the Audit team over a year ago. I don't know why I bother to try and write things out, to be helpful! They don't even bother to read the simplest things. What a waste of everyone's effort!

I also refused to allow access to my medical records by the audit team. Instead, I photocopied my records, deleting anything sensitive I did not wish them to see. This was a lot of work for me. I wanted to help the audit in any way possible to prevent it happening to other women. However, I was adamant that nobody but the doctor concerned should go through my records. I contacted my doctors and informed them that they were not to give my records to anyone. Most people in my situation want to see a purpose in their illness and make it worthwhile by helping others. If asked, they would cooperate with research. But to have their privacy invaded by strangers.....!! That is just too much on top of the loss

of privacy, dignity, and even life, that having cancer of the cervix involves.

I also wrote a long comment on how I felt cervical screening could be improved, especially the reporting of the results. If you wish, I could send you a copy of this. It is something I feel strongly about. That is why I am writing to you now. I have little time and energy, as fighting cancer takes up most of this, as well as a good portion of our disposable income as I am using my own resources, having lost faith in the system. However, I want my illness to have a purpose. For three years, I have struggled with the cancer and tried to draw the shortcomings in the screening system to attention. I am articulate, intelligent and concerned, and feel I can fight on behalf of other women. I feel research needs to be done. But those of us who have been affected should be consulted and respected. Then I am sure you will find that those of us who are well enough can turn our anger at the failure of the system into something more productive, to make sense of our experience and help others.

However, most of all, we must not lose the basic rights which we come to assume when we visit a doctor - namely, that it is a private consultation and that none of it will be divulged to a third party without our consent. This Bill takes away the safety women should have in discussing personal matters with their doctors and this will have a detrimental effect on women's health in general. And you will find people will opt off the Register, just as I did.

Surely common courtesy, let alone concern for the woman, should require consent. I am not a

political animal, but I will fight long and hard for what I believe to be right. And this Bill is not right.

Please can you think about what I have said. I would also appreciate a reply. As I said, I am willing to help in any way I can, except in the loss of my right to medical privacy. To me, that is the loss of a basic human right.

Yours faithfully,
Jenny Cocksey

It is strange. The report of the Cervical Cancer Audit was released on 19th November 2004, after a long wait. 1119 is the number which kept recurring in connection with my cancer and I had originally planned to publish this book on 19th November but time constraints prevented this. So it is strange that this report should be published on that date instead.

I found reading the full report and the statistical tables illuminating. My smears were reread in Sydney and found to be all read satisfactorily – there was no abnormality showing at all until just before my diagnosis, in spite of having had annual smears – six negative ones in all. However, this does make me wonder why Diagnostic Laboratories were so unwilling to let me see their in-house report on their own re-read of my slides. I find this disturbing.

My later slides were not reread and I am disturbed at this. I had tried to have them reread when I was first diagnosed and was told to wait until the audit did the rereading. I was not allowed to uplift them from the laboratory so that I could have them reread myself. So who actually owns these bits of me? I am still not convinced that some error was not made. And certainly the doctors and the laboratories were obstructive.

Whether this Audit makes any difference is arguable.

However, at least the problem of women getting adequate frequency and quality of smear-taking has been highlighted. Hopefully, it will have a beneficial effect on women's health and help prevent invasive cancer.

Women do need to be educated, however, on the importance of having regular smears and if they are in any doubt about symptoms, to push to a confirmatory one. The attitude seems just too casual. There also needs to be much more education on simple things that can be done to reduce the likelihood of low-grade cell changes progressing to high-grade and so on to invasive cancer, with all the heartache that that brings.

To Resthaven Funeral Services



To Resthaven Funeral Services

Fax 267 2560

Jennifer Anne Cocksey

Death Notice for New Zealand Herald for 16th April 2009

Dearly beloved, wife of Brian, yet so much more, mother of Nicki and Ran, sister of Judi, daughter of Dick and Marnie Mackesy, died on 14th April at 12.29am, her 19th wedding anniversary.

Jenny tried so hard at everything in life. She always gave her all. She fought cervical cancer for eight and a half years, despite the medical establishment. Jenny took a stand. She did it her way, God's way. God was always with her and now she is with God.

The doctors, nurses, staff and volunteers at Hospice South Auckland helped ensure that her

My Cancer Journey

transition from this world to the next was peaceful. The view from the window of the Rose Room could have been The Plains of Heaven, the Celestial City and the Rivers of Bliss.

Her funeral will take place at 11am on Tuesday, 21st April at St Aidan's Church, 23 Walter Strevens Drive, Conifer Grove, Takanini.

Brian Cocksey

15/04/2009 3:17:58 p.m.

Bibliography



I have added comments on how some of these books have helped me in my quest for information or support. Many of them I go back to again and again to refresh my memory, or just for reinforcement.

Meares, Ainslie MD – *Cancer – Another Way?* – Hill of Content, Melbourne.

Inspiring and the poetry helps get the message across.

Wade, Carlson – *Inner Cleansing* – Parker Publishing Co. New York.

I still find this book invaluable for its information on cleaning the whole system which I feel is a main key to getting better.

Fischer, William L – *How to Fight Cancer & Win* – Fischer Publishing Corporation, Ohio.

This was one of the first books I read which gave me hope. I felt I could overcome my cancer.

Finkel, Maurice – *Fresh Hope in Cancer* – Health Science Press, England.

Interesting overview of some unorthodox natural treatments – gives me hope.

Yance, Donald R. – *Herbal Medicine, Healing and Cancer* – Keats Publishing, Illinois.

An excellent reference book – helping to understand.

Gawler, Ian – *You Can Conquer Cancer* – Hill of Content, Melbourne.

Show it can be done. I also made brief contact with the Gawler Foundation which I did not find as helpful as the books. This is one book my doctor gave me to read when things got worse.